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The biographic impact of an HIV diagnosis (immune deficiency)

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THE BIOGRAPHIC IMPACT OF AN HIV DIAGNOSIS

BY

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Chapter 1 - Introduction

After more than a decade of public awareness, HIV/AIDS continues to pose a great challenge to individuals, families, institutions, governments and professionals. The numbers of those infected and affected is on the rise and it is now clear that no population or group of people can ignore this disease or its effects. This is a disease that can have a devastating impact on many aspects of life. As social workers, we must push forward in understanding and responding to the issue of HIV/AIDS. This research aims to further the understanding by demonstrating how an HIV diagnosis impacts on one's life story. The findings will be discussed in terms of their theoretical implications and importance for social work practice.

Social work, as a profession, has pioneered a response to HIV/AIDS (Haney, 1988; Ryan, 1987; 1988; Shernoff, 1990). The following statement demonstrates how the particular skills and positions social workers hold, allow us to be effective leaders in dealing with HIV/AIDS:

> Across the country, we social workers - gay and straight, women and men, policy planners, group workers, community organizers, clinicians, welfare workers, and administrators - have emerged as leaders and innovators in developing programs, identifying resources, providing essential training and critical services, and building community-based AIDS organizations: the cornerstone of each community's response to the epidemic. Our unique training as advocates, facilitators, and enablers; our capacity to negotiate diverse systems; and our wide knowledge base has prompted us to deliver crucial services at a time when governmental leadership and interest have been noticeably paralyzed to respond (Ryan, 1987, p. 1).

It would be a terrible mistake, however, if, as social workers, we felt our part was over, our work done. As long as this disease exists, there is a role for social work. And, the longer this virus exists, the more new issues will arise. Social workers must continually respond to the new demands that will no doubt evolve. The one area that social work has been criticized for not tackling in the field of HIV is conducting research (Schwartz, 1987). The need for this crucial part of a holistic response to HIV/AIDS has been identified by the Ontario Association of Professional Social Workers (1989) in their statement of social workers' responsibilities in relation to HIV/AIDS. They state that "social workers should participate in and/or initiate research on psycho-social issues related to HIV infection" (p. 3). This research does just that.

The reasons for focussing research on psychosocial aspects of HIV/AIDS is clear. To begin with, it is now recognized that illness - not just HIV - is a multidimensional phenomenon. All at once, it can have physical, psychological, social, economic and political impact (Furstenberg & Olson, 1984). In order to thoroughly understand the impact of an illness, all these aspects must be given consideration. Furthermore, research particularly focussing on HIV/AIDS and quality of life, has shown that psychosocial factors are the major determinants in the individual's level of quality of life and suggests that this is where attention should be focussed (Lubeck & Fries, 1992; Ragsdale & Morrow, 1990).

To date, research into the psychosocial issues related to HIV/AIDS has identified many ramifications of the illness that person's living with HIV / AIDS (PHA's) must deal with: stigmatization, living with uncertainty, unwillingly having to reveal one's sexual orientation or lifestyle, loss of a job, power, control, financial independence, self-esteem and relationships, a

sense of isolation and self-blame, fear for others and fear of death (Crandall & Coleman, 1992; Crystal & Jackson, 1989; Haney, 1988; Moynihan, Christ & Silver, 1988; Nicholson & Long, 1990; Weitz, 1989; 1990). Research and discussion on these issues has certainly increased our understanding of the multidimensional impact of HIV.

A new direction for psychosocial research on HIV emanates from the chronic nature of the illness. Tests allow individuals to be diagnosed earlier. Medications are available to prevent or treat recurring infections and health promotion strategies are being developed. All of these developments allow individuals to live for a longer amount of time, thus, HIV is now considered a chronic illness (Health and Welfare Canada, 1993; Schag, Ganz, Kahn & Petersen, 1992; Siegel & Krauss, 1991). When a person lives for a long time with HIV, a critical question is how does it impact on the individual's life. How does one's life change when living with HIV? This is the motivating question behind this research project.

Similar questions have been asked in relation to other chronic illnesses and have led to excellent discussion and theory on how chronic illness impacts on people's lives (Brooks &Matson, 1987; Bury, 1982; Charmaz, 1987; Cohen & Lazarus, 1979; Robinson, 1990; Taylor, 1983; Williams, 1984). For instance, Cohen and Lazarus (1979) have identified five tasks / challenges which the chronically ill must confront: 1) reducing destructive environmental conditions and taking steps to increase chance of recovery: 2) tolerating and adjusting to negative aspects of the disease: 3) maintaining a positive self-image: 4) maintaining an emotional balance: 5) continuing to engage in satisfying relationships. Similarly, Brooks and Matson (1987), from their work with people with multiple sclerosis, suggest that the adaption processes involve confronting the bodily changes that occur, using the social

environment to experiment with a changing identity and incorporating new idea. of self on a psychosocial level.

Taylor (1983) has studied the adaption process through working with people living with cancer. She suggests that when people face threatening events, such as illness, they adapt by searching for meaning - as to the cause, significance or symbolism of the illness; by attempting to gain mastery over the event - by gaining information and attempting to control the illness, its cause or its side effects; and by a process of self enhancement - generally accomplished by comparing one's self with those in perceived worse situations.

Fife (1994) has also done work with cancer patients and has focussed more specifically on the construction of meaning in the adaption process. In particular, she suggests that in response to the illness, individuals will reconstruct meaning in relation to the self and in relation to the social world:

> Within the context of highly threatening events, such as serious illness, the process of defining meaning involves efforts to understand and put in perspective the occurrence of the event, and to comprehend its significance for one's self and one's future life. (p. 311)

Research specifically related to HIV/AIDS has also focussed on the reconstruction of meaning. In a study of what gives PHA's meaning, purpose and value in their lives, Schaefer and Coleman (1992) found that one of the most important challenges encountered by HIV positive gay men was to redefine what is meaningful, purposeful, and valuable to them. Furthermore, the need to make sense of the illness and understand its meaning for the self and the future is also identified in the work of Sandstrom (1990). He

suggests that part of developing an AIDS-identity is to go through the process of finding the meaning of the illness.

Research on the adaptive tasks for PHAs found that focussing on individuals' search for meaning did not really capture the full nature of the adaptive process (Siegel & Krauss, 1991). Instead, Siegel and Krauss suggested the concept of biographical work as a way of conceptualizing the process of living with HIV: "we found a more comprehensive concept - biographical work - to be more useful in understanding our men's responses" (p. 28). While these authors identified biographical work as a way of understanding the adaptive process, the aim of their research was not to focus on this concept or identify how it is played out by PHAs. The aim of this research project is to explore the biographical impact experienced by PHAs.

Michael Bury (1982) introduced the concept that chronic illness leads to a biographical disruption. Essentially, he says that chronic illness acts as a 'critical situation' whereby the fundamental ways in which a person thinks about body, self, future and relationships are all disrupted. Biographic work then involves the reorganization of these things so that one's biography can continue. As Corbin and Strauss (1987) point out,

> when a chronic illness comes crashing into someone's life, it cannot help but separate the person of the present from the person of the past, and effect or even shatter any images of self held for the future (especially if the illness is severe or debilitating). ... New conceptions of who and what I am, past, present and future must arise out of what remains. (p. 249)

Corbin and Strauss (1987) go on to provide an excellent account of the biographical impact and work related to a serious illness. They point out that there are three major dimensions to a biography: 1) biographical time, 2) the body, and 3) conceptions of the self. Biographical time encompasses past, present and future time, clock time, and one's perception of time. The body plays a central role in that performances of action occur through the body. Conceptions of self refer to 'who I am' - views held of oneself in relation to all of identity (as opposed to simply referring to self-esteem). Conceptions of self are continually formed through, and in response to, the performances of action which the body carries out. The integration of these three elements, then, creates the biography - who I am as mediated through performances conducted by the body, at a point in time.

Chronic illness, however, will disrupt these three elements and, thus their integration. When illness ensues, the body may be seen as useless, a failure; performances may no longer be carried out; conceptions of self will be altered as a result; time will have to be restructured in order to manage the illness on a day-to-day basis. It will also change in a larger way, because the person in the present is not the person who was conceived of in the past. Thus, new conceptions for the future must also be developed. Furthermore, each of these points of impact has further implications for the other elements of the biography. Thus, according to Corbin and Strauss (1987), it is the chronic illnesses's impact on time, body and self that creates biographical disruption and necessitates biographical work for the continuation and meaning of one's biography.

To date, this theory and its application have largely focussed on the illnesses of multiple sclerosis and rheumatoid arthritis (Bury 1982; Corbin & Strauss, 1987). Applying it to new areas - such as HIV - may shed new light

on this theory and the experiences associated with other illnesses There are many aspects of HIV disease which differ it from other illnesses and, thus, may lead to differences in people's experience HIV is typically fatal It is a communicable disease It has perhaps the greatest amount of social stigma attached to it, and there is still so much unknown about it which means that people are living with extreme amounts of uncertainty (Canada's Mental Health, 1992; Macks, 1987; Schag et al., 1992). These differences warrant research on the impact of HIV on one's story and life

The focus of this research project, then, is to investigate what the biographical impact of HIV has been for HIV positive individuals I will explore how their life stories have changed since their diagnosis I will look at the impact on time, self and body as well as any other changes the individuals discuss. Thus, this research is examining how an HIV diagnosis changes one's life story - the biographic impact of HIV

Chapter 2 - Methodology

This research was exploratory, using qualitative methodology. No hypothesis was being tested. Rather, the aim was to explore how an HIV diagnosis impacts on one's life story. I will describe the theoretical orientation of this research, followed by a discussion of precisely how the research proceeded.

Orientation to Methodology

The research approach taken in this study is congruent with symbolic interactionist theory. Briefly, symbolic interactionist theory focuses on the interaction between the individual and the social world. It holds that the individual will attach meaning to events that occur and this meaning will be, and can only be, subjective.

> Meanings derive from the social process of people or groups of people interacting. Meanings allow people to produce various realities that constitute the sensory world (the so-called real world); but because these realities are related to how people create meaning, reality becomes an interpretation of various definitional options (based on Blumer, 1969 in Berg, 1989, p. 7).

Thus, in order to understand human behaviour, the perspective and experience of the individual must be examined. The question is how did the individual interpret the events in his/her context.

This theoretical approach is tightly connected to qualitative methodology. Qualitative methodology typically focuses on the individual in his/her context and aims to capture the participant's perspective on events. The goal is to provide "authentic data, namely, collecting and displaying evidence on the experiential side" (Gerhardt, 1990, p. 1149). With qualitative

methodology, then, the goal is to come as close as possible to knowing the meaning an individual ascribes to an event.

In this research, the question is how has the individual experienced HIV. How has his story changed as a result of diagnosis? The experience of the individual inevitably depends on his accumulation of experiences until now, combined with current interactions and reactions. Thus, the experience can only be subjective. The aim of this research is to understand the reality of the individual living with HIV and what this has meant for the continuation of his biography. Again, qualitative methodology is used to get an insider's perspective. This approach then, supports and fulfils the claim made by Joseph et al. (1984) that "any serious effort to study the impact of AIDS on gay men must attempt to understand the phenomenology of the crisis from the perspective of those exposed to it" (p. 1297).

Qualitative methodology aims to uncover the insider perspective, but because the interview and analysis is done by me, it becomes an interpretation. Thus, it is called the second order perspective (Gerhardt, 1990). Since I become the 'filter' of the information, it is important to provide some personal background here. My interest in the field of HIV / AIDS began when I took an undergraduate psychology course in the "biopsyhcsocial" aspect of AIDS. Because I was struck by the number of issues that surround HIV / AIDS, I have continued to study it during my graduate schooling. As well, I recently completed a four month practicum in the support program of an AIDS committee. I feel that the connection between HIV / AIDS and sexuality make it a particularly complex issue. My personal feelings regrading sexuality are that sexuality is an important aspect of our selves and life and that expression of our sexual selves, however we choose, is healthy. I personally am a straight female and feel that it is

important to point this out since I am interviewing gay men and am fairly unfamiliar with the gay community. I grew up in a city where the gay and lesbian community was very politically active, but except for a few relationships with gay or lesbian friends, I have had little personal involvement or interactions with this community. Thus, while I am supportive of the gay community, this research and my work at the AIDS committee were my first experiences of working with members of the community. As will be discussed later, this may have impacted on participants' comfort and willingness to discuss certain issues with me.

Conducting the Research

Key to carrying out this research was making a connection with a local AIDS committee. I met with the co-ordinator of support services at the AIDS committee to brainstorm possible research avenues. Discussions with her, reading some literature, and examining my own interests and observations led me to the current research question. A proposal for this research was written and submitted to the university's ethics board for review. The proposed research met with their full approval.

PHAs were selected for participation again with the assistance of the co-ordinator of support services. Initially I requested all participants to be homogenous with regard to gender, sexual orientation, age and stage of illness. The co-ordinator made an attempt at recruiting PHAs with these similarities but was completely unable to fulfil my request. We agreed that homogeneity of gender and sexual orientation would be sufficient. My thinking was that the experience of living with HIV may be too different if men and women and heterosexual and gay and lesbian individuals were all included. Furthermore, past research suggests that stage of illness does not significantly affect the individual's experience of the disease (Lubeck & Fries,

1992). Thus, all participants were to be g ay men, but age and stage of illness would vary.

For confidentiality reasons, the co-ordinator of support services made the initial contact with PHAs. It would not have been appropriate for her to give me the names and numbers of service users. She told them about my research and gave them my name and telephone number to contact if interested. Four individuals contacted me, expressing interest in my research When they phoned me, I read a script that outlined the focus and purpose of my research, and what the procedures for participating were (see Appendix A). After this script was read, the individuals were given the opportunity to ask questions, raise concerns and / or decline to participate. All four individuals said they were interested, and so at the end of each phone conversation, a time, date and place for the interview was arranged.

Thus, the number of participants for this research was four. Full case histories and stories of the four individuals are presented in chapter 3. Such a small number of participants, of course, restricts the generalizability of this research. A small number of participants were interviewed mainly because of practical reasons. First of all, only four individuals volunteered to participate. Secondly, I wanted to maintain a low number so that this project would be manageable in a limited amount of time. I am not concerned about the small number of participants because my aim was not to generalize my results to other PHAs. Consistent with qualitative principles, my goal was to learn, in depth, the experiences of a few PHA's, rather than to learn a restricted amount about a large number of PHA's (Kirby & McKenna, 1989; Lincoln & Guba, 1985).

Participants were always given the choice of where they would like the interview to take place. Two of the interviews were held at the AIDS

committee and two were held at participants' homes. Before the interviews began, participants read and signed a consent form (see Appendix B). This consent form outlined the purpose and focus of the research, possible risks and benefits to participating, the procedures involved in conducting the research, and methods for maintaining confidentiality. Participants kept a copy of the consent form. Background demographic questions were asked at the start. These questions covered, age, occupation, educational background, income level, single or with partner, stage of disease and their experience with HIV related illnesses.

A semi-structured interview format was used to discuss their experience with HIV. The interview generally began by my introducing the research question of 'how has HIV changed your life story?' Participants then freely discussed their experience. New questions or discussion were generated from points and comments participants made. Participants had a general idea of what issues to cover as our telephone conversation and the consent form outlined the focus as being how their life, their self and relationships had changed since diagnosis. However, six topics were always addressed: changes in regard to physical health, self, time, work, relationships and family. If participants did not bring up one of these topics, then I would ask about them in a general but direct question: i.e. 'Can you tell me about any changes in your relationship with your family that you have experienced?' The reason these topics were discussed was because they are critical to the framework of biography and illness. Thus, in order to understand the biographical impact of HIV, these topics needed to be discussed.

The interview process was very relaxed and informal, particularly once the first five minutes passed. Participants seemed to share openly and

eagerly and there was a lot of laughter throughout the interviews. The interviews lasted between 1 and 2 hours. All interviews were tape recorded with verbal permission of the participants. At the end of each interview, participants were told they would be contacted in the next three months to discuss the findings. Furthermore, in completing the interviews, all participants commented on enjoying the experience of telling their story, stating that they felt it was important to contribute to research One individual, at a later point, phoned the co-ordinator of support services to tell her how much he appreciated the opportunity to participate and that it helped him think about his experience in some new ways. Overall, I was greatly impressed by and appreciated the cooperation and enthusiasm of the participants and the support co-ordinator.

After the second and fourth interviews, I met with a colleague for peer debriefing. I discussed with him my experience of the interview and also some initial thoughts on what participants had shared. I also kept a journal on the research process, and here, commented on my reactions to the process and content of the interviews These steps were taken both for my own support and also because they are considered important to maintaining trustworthiness in qualitative research in order to track and check the process of the research and the logic behind my ideas related to the data (Lincoln & Guba, 1985).

When all the interviews were completed, they were transcribed. During the transcription, participants names were changed to false names, punctuation was added and comments such as "Um" or "Ah" were eliminated. Each interview was approximately 20 pages in length.

The next step in the process was data analysis. I first read over all the interviews and made comments on the process and content as they related to

both participants and myself. I then began the "constant comparison" method of analyzing the data (Kirby & McKenna, 1989; Lincoln & Guba, 1985). I read over all the interviews and created general labels or codes that I felt described what was being talked about by participants. This created an initial set of eighteen codes. I then reread interviews several times and applied the codes that had been created during the first reading. At this point, it became apparent that certain codes were always being applied together. Therefore, these codes were rethought until a single term that captured the 'wholeness' of the topic was found. A final set of eleven codes was created. The next step was to file the similarly coded material together, creating categories or files.

Next, material in the files was compared and re-filed based on its similarity. Generally, I was looking to see if material was about the same thing, i.e. was the topic similar. What participants were saying about topics often differed, but it was important that files or categories were based on the same topic. From here, I defined what criteria constituted inclusion in the category and then came up with final category names for the eleven codes. The resulting eleven categories were then the categories of biographic impact that occurred for these individuals following their diagnosis.

During the coding and 'becoming involved with the data' (Kirby & McKenna, 1989) a certain pattern began to emerge. Three of the categories seemed to be responsible for the other categories: they were either always applied at the same time, or events in the remaining eight categories made sense only in light of the other three categories. This hypothesis was tested using negative case analysis. Using this method, the categories were re-examined against the hypothesis to determine "the fit" of the raw data with the hypothesis. Lincoln and Guba (1985) suggest that at least 60% of the

cases should fit the hypothesis. This quota was met in this research as the vast majority of changes were accounted for by changes in three of the categories. A full description of this theory and the eleven categories will be given in chapter 4 on analysis.

The small number of participants posed a limitation to the analysis. Typically in qualitative methodology, the collection of data ceases when no new material is being offered. This is called the point of saturation (Kirby & McKenna, 1989; Lincoln & Guba, 1985). In this research project, however, the number of participants was predetermined, so the point of saturation was not met.

When the analysis was completed, participants were contacted and given a copy of the analysis. I asked them to review the analysis to make sure that my interpretation was consistent with their experience and that what I said about them was accurate and acceptable to them. Participants supported my interpretation and felt that it accurately captured the experience of living with HIV. They all felt comfortable with the research process and gave some suggestions for future research. These will be discussed later.

The next step was to compare what was found in this research with existing theory on biographical disruption, chronic illness and HIV. This is presented in chapter 5. Finally, chapter 6 looks at how the findings and experiences of these individuals relates to social work practice.

Chapter 3 - Introduction to Participants

All participants were gay men who lived in the local community and were patrons of the AIDS committee. Their individual histories and stories follow.

MARK

Mark was 31, single and lived alone. He had a Bachelor of Arts degree in English and a diploma in accounting. He worked as a researcher and resource officer earning between $30,000 and $40,000 / year.

He was diagnosed with HIV in July 1993 and was asymptomatic.

After diagnosis, Mark became very politically active and particularly active at the AIDS committee. He also strengthened and developed many new relationships. Some old friendships had been lost. His relationship with his mother and father became closer, sharing some very intimate conversations. Distance had grown between him and his brother.

Before his diagnosis, Mark said he was very concerned with things like "beauty, sex, money, fun". After diagnosis, much of this changed: visual appearance and thus rigid works-outs, diets and clothing, were not as important. He said he was more interested in inner rather than outer beauty. His ideas around sexuality were challenged and redefined to include safer sex practices and new ideas about sexuality and relationships. He no longer maintained the idea that "the more beautiful you were, the more sex you got; and the more sex you got, the better".

Mark became less interested in his career following his diagnosis. He did the necessary work, but not the 'extras'. He said that he was not sure that he would be around for the 'pay off'. Other things, such as relationships and political activities, became more important. Mark said that he wished he

could retire now so he could have time for himself, relationships, and his own interests / activities since he probably will not reach retirement at 65. Knowing that he might not make it to old age pushed Mark to do some self-work and relationship-work now:

> I think I was also pretty content to let stuff with my parents drift along. Thinking there was lots of time for that to evolve. Same with some of my friends. Thinking there would be times when we'd be sixty, sitting on a porch in rocking chairs and having time to do that kind of stuff. And all of sudden all of that stuff is moved up to now.

Overall, he said that after diagnosis, he became a more assertive person and more caring about his relationships with others.

JEFF

Jeff was 35 and lived with his partner. They had been together for a year and a half. He had a daughter and an ex-wife who lived in another city. He had a Bachelor of Arts degree in geography and history and a business diploma. He was on a disability pension, thus his income was around $10,000 / year.

Jeff was diagnosed with HIV in 1989 and it had progressed to AIDS. His partner was not HIV positive.

Jeff talked about his experience with HIV in a stage like process. The first stage, when just diagnosed, he called the 'freak out' stage. He said that this period was filled with shock and the idea that you are going to die tomorrow. He did not tell anyone about his diagnosis so went through this time alone. As well, at this time in Jeff's life, he was ending a relationship

with a partner and moving to a new city. (These plans were made prediagnosis.)

For Jeff, the next step involved learning more about HIV and beginning to deal with it and its ramifications. He became involved in the local AIDS committee, joining a support group, and then later, committees at the provincial and national level.

Not long after his diagnosis, Jeff left his job in the banking industry. He left it to bartend as this was something he always wanted to do. Eventually bartending became too physically draining, and Jeff went on disability benefits. This led to big changes in lifestyle as he was only receiving about $10,000 / year. When banking he was earning around $75,000 / year. He also found it difficult on his self-esteem to know others were going to work but he could not. At one point he went back to work at the AIDS committee, but when this became too much, he had to go on disability pension again.

The third stage, where Jeff felt he was now at, involved dealing with friends and family. Jeff said that following his diagnosis, he and his parents talked about a lot of issues and they were extremely supportive. He had some difficulties with friends who were not very understanding or sensitive. He said some of his other friendships, however, improved and were "a lot more meaningful, more levelling, more honest". Jeff also talked about some of the pain related to the possibility of not seeing his daughter grow up.

Jeff's illness had progressed to a point that activities were often too draining for him. Thus, things like socializing and housework were kept to a minimum. For Jeff, these losses were often difficult, but he worked to "keep it in perspective" and had a very positive attitude.

Contributing to the AIDS committee was very important to Jeff and he

said that he had learned a lot through this. He emphasized how much PHAs have to offer and felt that he used his diagnosis to sharpen his skills at sharing and presenting information to others.

DEREK

Derek was 36 and recently separated from his partner. They were 'married' about a year ago and had been together a year and half before that. He had a university degree and worked at the AIDS committee as the positive approaches co-ordinator, providing health education, health promotion and advocacy for PHAs. His income level was around $30,000 / year.

Derek was diagnosed with HIV in 1991 but suspected he was infected long before this time. He was symptomatic and was not at all well the day of our interview.

Derek's work at the AIDS committee was extremely important to him and he said he got a great deal of satisfaction out of his work and public speaking. Being involved at the AIDS committee and establishing relationships through there had helped him to slow down his l[illegible]nd enjoy others and living more. "The incredible gift of people and what I learned from them and what they gave me. It's changed me psychologically, it's incredible. I've learned to be less judgmental of people, less judgmental of myself".

The physical problems related to HIV (fatigue and gastrointestinal problems, in particular) created difficulties in Derek's life. He talked about the uncertainty and unpredictability about his health and how this restricted activity involvement. Daily routines were exhausting for him. He also felt his recent break-up was related to his diagnosis and health problems.

Because he was not feeling well, he was not be able to do as much as his partner and his partner found it all too difficult. His ex-partner's family was the family that Derek had connections with, as he was 'divorced' from his own family. His in-laws were very close to him, but remained fairly distanced to the issue of HIV. His father-in-law, however, was interested in learning about the illness and other members, at times, showed support. He said that some friendships had "fallen by the way-side" and his social circle had grown somewhat smaller.

Despite these difficulties Derek was facing, he maintained a very positive attitude. He emphasized the value he felt from his work and how he had become a "nicer, gentler person". He had begun to develop and explore the spiritual aspect of his life and emphasized looking at the positives and simply letting the losses go.

CRAIG

Craig was 32 and lived with his partner in a home they had recently bought together. He had a diploma in computer programming and did computer work for an insurance company. He was earning between $40,000 and $50,000 / year.

Craig was diagnosed four and a half years ago and was asymptomatic. His partner was not HIV positive.

The big change for Craig following his diagnosis was the ending of a relationship with a partner he had been with for ten years. After his diagnosis, Craig said he felt he wanted more closeness and emotional intimacy. His relationship at that time was quite cold, and after a period of

trying to work things out with his partner. Craig felt he could not get what he wanted in that relationship

Related to this, Craig went through some real "self" changes Before his diagnosis, he said he was quite shy and hesitant in relating with others Following diagnosis, however, he worked on breaking down some of his emotional barriers and became much more self-confident and open with others

Craig enjoyed his job but had not disclosed his diagnosis to his colleagues. He was contemplating doing this, he wanted to disclose so that he could go more public with his experience (i e public speaking) and felt that some of his co-workers would be very supportive He was concerned, however, that managers may not pay for further training for him if they thought that he would not be with the company for a long time Craig identified this as the major dilemma for him at this time

Craig's partner, friends and family were all supportive of him His family lived in another province so he did not have much contact with them

Craig aimed to live a very consistent and healthy life He exercised regularly and was very conscious of his diet He talked a lot about having a positive attitude and felt that all this was important to his surviving HIV

Chapter 4 - Analysis

The stories of these four individuals reflected many biographic changes after their HIV diagnosis. Using the inductive method of constant comparison, biographic changes in 11 areas were identified. These areas of change were: time, focus (defined as what is important to the individual and his attitude or approach to living), the presence of illness, self, relationships (friends and partners), family (defined however participants wanted, but typically was family of origin, or, in one case, family of origin by in-law), lifestyle, work, community, health activities and sexuality. As this was inductive research, these categories came directly from the data. That is, these are things that participants talked about. The terms, however, I have applied to their experience. Participants did not necessarily use these terms. Furthermore, because a semi-structured interview format was used, I introduced some of the topics. Similarly, all participants did not necessarily talk about all categories, though in most cases they did. Table 1 outlines the eleven categories of change and identifies which participants talked about the area and whether the participant or I initiated the topic.

Insert table 1 here

The areas in which I particularly initiated conversation were changes related to time and family. As well, as indicated, only in one case was sexuality discussed. Possible reasons for these occurrences will be discussed later.

These eleven categories of change were further analyzed using negative case analysis. During the reading and coding of the interviews, I began to sense that many of the changes that occurred could be explained by the changes in time, focus, and the presence of illness. These three changes

seemed to be influencing the rest of the changes. This theory was tested using negative case analysis. This process involved re-examining the information in eight categories in light of the hypothesis to see if they 'fit'. Indeed this hypothesis was confirmed. As will be demonstrated, changes in sense of time, one's focus for living and the presence of illness all played a major role in structuring one's story. They were like primary changes and the other eight changes, secondary. Hence, the many changes in these individuals' biographies can be understood within the framework of these other three changes. Furthermore, as will be seen, many of the secondary components also affected one another - i.e. changes in self can lead to changes in relationships. A diagram of this theory and the interactional nature of the elements is presented in figure 1.

Insert figure 1 here

The interactional nature of these categories makes it difficult to talk about changes in one category without talking about changes in other categories. Thus, the isolation of categories is for theoretical discussion, but in reality, these categories are very fluid.

I will now describe the changes and the directing role of these three fundamental components - time, focus and illness - and will describe the secondary changes they promote. First, I will describe how time is viewed following diagnosis and then briefly point out some secondary changes that this created. Next, I will show how one's focus changed and again discuss some of the resulting secondary changes. I will then discuss how time and focus interacted, and thereby, created many secondary changes. Finally, I

will talk about how the presence of illness also played a directing role, accounting for many biographic changes.

Time

Time is a central concept to the telling of one's story. We talk about what happened yesterday, what we are doing today, what we hope for tomorrow. Events are placed in the contexts of hours, days, weeks, months and years. Life is placed on a time line of birth to death.

Not surprisingly, time evolved as a critical concept in the stories of the four PHAs. It was a foundation component as it gave the structure to one's story: it influenced and was influenced by other foundation components; and, it affected other aspects of the story.

On the direct level of the time span of one's story, there were two sorts of changes: the changing sense of time that came upon the shock of the initial diagnosis, and a more permanent sense of change as the diagnosis was incorporated into one's biography. When first diagnosed HIV positive, there was a great crash in time: time was lost, the future was non-existent, as the diagnosis was like a death sentence. "Well, I think the first thing you experience is that loss of the future. More because you don't know how long" (Derek).

> For a while I felt, even though I tried not to, I felt like I had sort of lost a future. I would say for about the first year it was very difficult to know whether to plan, whether to work hard at stuff, whether to worry about anything. It was sort of a year of confusion (Craig).

Once the initial shock of diagnosis settled - as Jeff says, once the "freak out" stage ends - individuals did see a future biography, but it was

different from before diagnosis. A future once again existed, the biography went on, but in a transformed way. "I've regained that [a sense of future] but in a kind of transformed way. Like I still have a future and I think about the future and have plans for my future. ... It's just a different quality" (Mark).

For Mark, one way the quality of future was different was it did not involve long term plans. He chose to not embark on projects that may take a few years to complete or pay off: "I'm more likely to do something that is for a few months. I don't have any plans that extend for years and years. I recognize I could get sick tomorrow so I don't want to have a lot of loose ends."

Jeff too continued to plan for a future, however long or short that may be: "I think as long as I have a sense of future, am making sort of tentative plans for next summer sort of thing, is helpful and health promoting. Because it would be easy, and people do just give up. Like what's the point, I'm gonna be dead anyway. ... I think that's the one thing that keeps me going is the sense of future" (Jeff).

As is heard in Jeff's statement, continuing to have a sense of, and planing for a future was very critical to their mental health. They recognized and acknowledged that they may die earlier than once thought, but planning for a future kept them going. To not plan for the future would be like giving in now, ending the story without living it through to the close. "I can't short plan my life. ... I mean I really don't think about not making it to retirement and stuff. I mean in all likelihood I probably won't, but I think not planning for it means I have a lot better chance of not making it" (Craig).

Time that structured the present biography was also altered. What emerged was that time in the present involved a sense of urgency. "It's kind

of a sense that I don't have a lot of time and that to get what I want out of my life, I have to do it now" (Mark).

> I know I'm only talking about a few years - I don't have a fatalistic outlook - it still gives you that sense that there are things you have to do now. So there's a sense of urgency in getting things done. ... More because you don't know how long. Even in the broader sense, we're talking 10 to 13 years and that's upon diagnosis and what if I've already been HIV positive for 10 years. So you really don't know. So there is a sense of urgency and I've done some things that I've wanted to do. But there's times when you can't, you're just not well enough. So it's kind of like grabbing time for what it's worth (Derek).

Related to this, as time was urgent, it also became very valuable. For these four individuals, present time, and all time, was precious. It was valued more, and therefore, used in ways different than before diagnosis.

> Now I'm much more thoughtful about what it is I do with my time and what I have to give up if I want to make time to do something else. ... I think time is a lot more valuable and I'm more conscious of how I spend time. I think time is much more limited than it used to be. If I want to make the most of it, I have to put energy into it. I find I'm much less likely to be bored or, say, watch TV. I'm much more motivated do things, use my time in productive ways (Mark).

The fact that there is most likely less time, made today's time, more important: "That the idea we're all gonna die but those of us with HIV are gonna at a younger age, I think prompts that too - you know who knows how long I'll be here. Sort of makes time more valuable" (Jeff).

While time conceptions for one's biography for the present and the future indeed changed, conceptions of the past remained relatively stable. For these individuals there was a slight feeling that more could have been made out of the past, but for the most part, they look forward, not backward. "I don't sort of live in that regret thing. As for going back and changing it, I sort of look the other direction and forwards because there's nothing you can do about it anyway" (Jeff).

> I think I could have got more out of the past if I had similar attitudes about time lines. In a sense, I have a vague feeling that I wasted time or went off in directions that were not that productive. But I know I can't change the past. I think I did what I wanted at the time. It's just that that's changed now (Mark).

Craig, while not dwelling on the past, did talk about the joys in remembering the past.

> I think I get a lot more out of doing things like going through photo albums and things. I mean I used to put photos in an album and never look at them again. And now I go through and it does trigger. I spend a lot of time going through and remembering good things. I don't really dwell on the past that much. Partly because I don't have a good memory. But I think the past has grown in importance for me because I like to remember the things that I've done, the good times I've had.

Time was a central concept to the biographies of the four individuals. It was the structure for their stories. It involved a definite future that accommodated diagnosis by being perhaps shortened or with an acknowledgment that it may end early. The present was marked by a sense

of urgency and valuing one's time more. The past story was given little attention, with today and tomorrow holding key importance.

Time and Secondary Biographic Changes

The effect of these aspects of time on the rest of one's story was evident mainly in combination with the other foundation elements. This will be outlined as the components of focus and illness are each discussed. There was one way, however, that this changing sense of time directly created change in the secondary element of family. Jeff and Mark talked about how their relationships with their parents changed following diagnosis. Parents seemed to recognize as well, that the future may be shortened for their sons and so interacted in new ways because of this.

> I told my parents about 2 months after I found out. At first they were really concerned. Like they thought I was gonna die in a day, spending a lot of time with me, checking up on me, that kind of thing. It's kind of eased off and they seem a little more comfortable with it. I really raked it in the first Christmas (laughter). My parents are much more likely to give me things, give me money, whereas before they would just let me work out my material concerns myself. At first, whenever I went to see my mom, she wanted to write me a cheque, give me something, furniture, a microwave or buy me something. That kind of thing has changed. ... I think my dad is much more emotional when I'm around. I think he's kind of confused about how to express that (Mark).

> There's also the reality, they're [his parents] in their 80's, so they're older. In terms of their estate planning, it's probably not gonna go the

way they always thought it would to where their children would inherit their estate, so they're giving me parts of my share now (Jeff).

For Jeff, the loss of a long term future also meant touching on the fact that his story would change in terms of what he might experience with his daughter: "I have a 14 year-old daughter who lives with her mother in London. And all that sort of thing. You know, I'll never see her get married".

So with the changed sense of time, family relationships and interactions were also affected. Family members acknowledged that the individual may not live as long, and, therefore, changed their behaviour to try and make up for that, where possible.

Focus

The second foundation element that emerged from the stories was what I termed the focus component. It involved the individual's focus for living: what was important, how the individual looked at things, his attitude toward and perspective for living in general, and with HIV as a part of that. The focus reflected values and priorities. It was like a philosophy for living. Choices about living were made based on these principles. Many of the story changes stemmed from the changes and developments at the level of focus. The focus, in essence, like the other foundation elements, gave direction to the biography.

The change of focus is reflected in the following statement by Derek: "Your whole philosophy around life and living changes. Your attitude changes, definitely for the better". Participants rarely described specifically

how their focus had changed. Rather, it was inherent in the decisions they made and their talk about the motivations behind the decisions. Developing or changing their focus of living involved two inter-related parts: making decisions about what was important to them, and embracing a way of looking at things, an attitude for living.

Before developing a clear sense of 'what is important to me', individuals often went through a re-evaluation stage. After diagnosis, past assumptions about what is meaningful and important were thrown into question. Jeff described it as "stepping back and looking inside". This period of re-evaluation was like a transition period, a time which could be very difficult.

> I felt like I wanted things but I didn't know what they were. But I think we need that change. It's like a transition period. Before I knew what I wanted for my relationships and then I felt like I was getting what I needed, but I wasn't sure what exactly it was I wanted. ... It was like wandering around, not knowing what you're wanting. It was frustrating and confusing (Mark).

Craig too talked about a sense of wanting something else but having to figure out what it was: "Looking at my life, and realizing that my relationship is not what I want, and why isn't it what I want. ... I went to a therapist for about a year to work out some issues about who I am and where am I going".

For Derek, the re-evaluation stage involved making sense of his diagnosis; deciding what sort of significance it had:

> There's a lot of searching out. Sometimes I look back and when I first started getting involved it was because I was losing so many

> people. You know one summer I had gone to over fifty funerals. So it had such an impact on me. And coming from the background I have, I was a media broadcaster. I never worked in social services or anything like that. And I remember those first few years I would think how did this happen, what am I doing this for? So I think it's becoming clearer. And then finding out my diagnosis. It was like wow there's some sort of path here and some reason that I've been here.

The changing sense of time also played a role in triggering the re-evaluation: "Thinking about, well, having to put some sort of a time frame on how long you're gonna be on this planet. And figuring out what is it I really want to do and can I accomplish that." This statement of Mark's reflects how the two foundation elements interact - the changed sense of time led to the process of determining what was important to the person.

Following diagnosis there was a movement away from external success oriented priorities. Valuing oneself, intimate relationships, and contributing to the AIDS and /or gay community is what became and is important to these four individuals. Many of the story changes reflected these values.

Mark in particular talked about his story before diagnosis being driven by values related to job success, appearance and sex. Self-esteem and relationships were based on:

> beauty, sex, money fun. ... How many work outs I did and when I stuck to my diet and the clothes I wore. That kind of thing. Meeting new people in bars and flirting with people. The number of people I slept with and that sort of thing. All those sorts of things contributed

> to what I thought was where I wanted to be and the kinds of things I wanted to do.

Following diagnosis, however, these were no longer the things that were important to Mark:

> Now I'm much more interested in what's going on in people's lives and how they're coping with that. And having people listen to what's going on with me, that sort of thing. And I really don't care about my statistics [at work], that sort of stuff. I'm much more interested in: I could be reading this article in AIDS, or sitting doing something else, or making phone calls for some volunteer work that I have. That kind of thing. ... I'm much more involved in the community than I ever have been before. I think testing positive was certainly a catalyst for me to do something about my political beliefs.

The new importance of relationships was also heard in Derek's story as he said that after diagnosis he started "really cherishing the people around me and letting them know that through different means and really sort of valuing that".

Craig too, spoke of the importance of deep, intimate relationships. In determining that this was important to him, he realized the problems related to his previous feelings about relationships:

> I realized that maybe that was a part of what led to my becoming infected with HIV in the first place was that looking for intimacy but finding it in the form of sex, which is the classical North American problem that we have from what I read. That people go looking for

> that intimate contact and think that sex is what provides that, but in the end it doesn't.

Furthermore, contributing to the AIDS community was very important to these individuals. This was heard above in Mark's story and was also reflected in the stories of the three other individuals. Craig said that he wanted to disclose his diagnosis at work so that he can do some public speaking about his story.

> I have thought of getting involved in the speakers program for ACCKWA because of the fact that I've been diagnosed for five years and am healthy and don't plan on dying any time in the near future. But I can't do that if I'm not open at work. Because I would prefer they heard it from me and not from someone that knew someone that was at some talk.

Similarly, Jeff and Derek talked about how important it was for them to share their information and experience with other PHAs. "You start realizing you have a lot more to offer and those other people with HIV need what you have to offer" (Jeff). Earlier, Derek talked about how he felt there was a path he was following which brought together his diagnosis and his involvement in the AIDS field. The result of this was a real commitment to his work and community involvement: "So now I really want to use that experience, that knowledge to help other people. That's really my primary goal right now. Because I know I needed another PHA to talk to and now I've done that for other people."

Another area that was affected by the changed focus was one's self concept. More specifically, they seemed to value themselves more, giving

more importance to their own feelings and needs. "I've seen a big change in myself in that area [self-esteem] because now I realize I am the most important person to me and no one else can take that away form me" (Craig). "Whereas after diagnosis, you basically say fuck the world and now it's my time of doing what I do for me that will keep me alive longer" (Jeff).

These statements reflect the participants' newly developed priorities which gave direction to the rest of their story. Jeff described it clearly as "planning what's important to me. You know, 'cause if I have two years left or if I have five, it's important to have some direction." So a big part of forming one's focus for living was determining what was important to each individual.

The second aspect of the focus component was developing an attitude or perspective for living, an approach for dealing with HIV, and, in general, for conducting one's life. A big part of this involved focussing on certain things, seeing some old things differently or letting them go. "There's a sense of looking at a lot of things that I never used to look at and I think a lot of them have a spirituality edge to them. ... And opening myself up to that. New age things, things I would have been very skeptical about before" (Derek). "You look at people much differently and weigh your relationships much differently, whether you want to admit or not" (Jeff). "I've become a lot more interested in sort of spiritual and emotional growth areas" (Craig).

> And then there's learning to just let things go. You know, the little things in life that used to irritate me. There's just more important things to me. Just let it go and try to enjoy each day for what it is, for what you have, for the people around you. You try to find some small beauty around you (Derek).

Similarly, individuals adopted a very positive attitude for living Participants again and again commented on how they looked for the positives in others, their situation, and life This was the attitude with which they approached living and thus, which directed their activities and stories. "You know, you're either very down and give in, or you stand up and make a life for yourself" (Jeff). "When I go out and do my speaks, I talk about the positives and maybe down play the negative part You know, like we're not victims" (Derek)

> Now I still acknowledge the fact that something could happen and I could get sick tomorrow you know. I mean there's extenuating circumstances like you're in an accident or there's some trauma that causes your immune system to fail and if that happens then maybe it's a downward slide from there but then that's like worrying about getting hit by a car You know, it could happen and it's not worth worrying about (Craig).

What is clear from the above discussion is that following an HIV diagnosis, the four individuals developed a focus that involved a positive attitude and approach to living. They also established what was and was not important to them. This focus was like a set of personal values for living This focus played a major role in framing and influencing the many other biographic changes which occurred. While its influence on secondary elements has already become apparent in the above discussion, I will now give further examples of these biographic changes. I will then demonstrate how the focus and time elements interacted to direct many of the other changes. What will also be evident in these examples is how changes in one secondary element also influenced other secondary elements

Focus and Secondary Biographic Changes

To begin with, participants talked about how their self concept, particularly self esteem had changed since diagnosis. Self-esteem was bolstered by engaging in activities that were supportive of the values described above. For instance, when I asked Mark what sorts of things contributed to his self-esteem, he said:

> the kind of work I'm doing in AIDS. ... And I think my willingness to listen to other people's stories and their issues and trying to understand. .... I like connecting with other people that have similar interests that I do and want to work toward common goals. Being involved in the community and trying to change the stigma around HIV, being gay or lesbian. Learning about myself in therapy is very interesting and rewarding, challenging.

Similarly, Derek talked about how his new approach to living which involved letting go and slowing down, really affected his sense of self:

> I'm kinder and gentler on myself. Yeah, because I used to be this real frantic person. All these things that happen in life that you can't do anything about used to drive me nuts. I was so uptight. I would just want to GO. ... It's changed me psychologically, it's incredible. I've learned to be less judgmental of people, less judgmental of myself. Not as hard on myself cause I used to be really hard on myself and others. Learning to just take people as who they are and not judging them anymore.

One of the big focus changes for Craig was seeing himself as most important. This too had a great impact on his self concept. "I think I'm a lot

more confident in myself now. I used to hold back a lot. Thinking if I expressed myself, I might be hurt somehow. . . Yeah I feel so much more comfortable with myself" (Craig).

For this individual, putting himself first also meant getting in touch with emotions and thus becoming a more expressive person:

> I used to have a lot of sort of walls around my emotions and didn't really demonstrate them very well. And actually, I couldn't even acknowledge them in myself very well. That's why I couldn't demonstrate them. ... A lot of those barriers are gone and now I know there's no reason not to express myself (Craig).

In Jeff's story, it was clear that a positive attitude and focussing on new things helped him deal with the attacks on his self-esteem that happened as a result of the losses related to HIV:

> I think that the losses sort of philosophy ties directly into your sense of worth because you have to put that into perspective. ... So there's blue days where you go though these feelings and it's just like putting it into perspective and saying the reality is you can't, so get with it. So what are you gonna do to compensate for that.

For Jeff, one of the main ways he compensated for this was by getting involved in the AIDS community. Again, a value that emerged at the focus level.

> So I think, yeah, there's lots of good about the diagnosis and part of that is sharpening my talents, learning what I'm better at and the sense of satisfaction of having gone out and done something about that. I mean with public speaking, I never would have done that. I always

> hated it, prepared script. But I never go with notes or cards, nothing, because I'm talking about my experience. I'm talking to high school kids, groups. So that's like a big change in a good way. So it's not just the helping of others, but you're helping yourself.

Derek had a similar story of getting involved in the AIDS community, both through work and volunteering, and this being important to his sense of self.

> I'm getting such a great deal of satisfaction from the work that I do [at an AIDS committee]. From the feedback I get if I go out and do public speaks or something. So that helps put a lot of things into perspective. ... I go to as many things as I can, you know in print, on the radio and I do speaks as much as I can. ... And I've done a lot of speaking and it energizes me.

Maintaining a positive attitude also helped structure Craig's mother's response to her son's diagnosis.

> Obviously it was very emotional. I think that a lot of my belief system and my outlook on life comes from my mother. You know, no matter how bad things get, there's always something better and you just keep working and you go ahead and you just always keep looking for the positive side of things, believe the best in people and that stuff. So after a couple of days - and I told her that I got a lot of that from her as well and that I really appreciated it. And I think that helped her to see that my attitude is going to help me stay healthy for a lot longer than if I was sort of accepting death. So we're a lot closer now.

Thus the positive attitude was important to how Craig's experience with his mother unfolded. Craig's relationship with his partner also changed. Here again, is another striking example of how the new values and focus promoted other biographic changes.

> When I was diagnosed, I was involved in a long term relationship. I had been with my partner at that point for almost 10 years and it was a relationship that had grown very distant and cold. I was comfortable with that for a long time. But after my diagnosis, it kind of, it didn't feel right anymore. At that point, I started thinking I want contact. I want intimacy. What I was looking for - sort of physical and emotional intimacy, but not necessarily sex. And when I finally realized that and talked to my partner about that, he was unable to provide that for me because all of his own baggage he was carrying. You know, he was not at a place where that was something he could do.

One final area that was altered was the component of sexuality in Mark's story. This change reflected the new focus he developed which values intimate relationships and puts priority on internal matters and less on external, visual qualities. When first diagnosed, Mark felt

> people would be really reluctant to get involved in a sexual relationship with me. And anyone I would date would secretly be suicidal. I think my expectations about relationships have changed. I don't think sex has such a high priority in a relationship. I think I've learned a lot more about sex since being HIV positive since I've had to alter my sexual practices to ensure not transferring HIV to my sexual partners. So I think that I am much more open to experimenting

> sexually. ... I think about myself differently too, like in terms of my attractiveness, my sexuality and how those things are related to each other or not related to one another. ... I'm much more attracted to all that stuff with relationship than I am with people with just that sexual aspect. That kind of thing. I don't think beauty is that visual quality that I thought before, within myself and with how I evaluate or judge other people too.

For Mark, his sexuality was reframed within his new focus and approach to living.

Focus, Time and Secondary Biographic Changes

Many of the other biographic changes that the four individuals experienced can be understood by looking at how the foundation elements of time and focus interacted and worked together to structure one's story. As stated earlier, after diagnosis, time took on a sense of urgency for the individuals. This, in part, triggered the crystallizing of one's life focus: there was limited time so it was important to determine what one really wanted to do with that time:

> loss of my vision of the future, and thinking about, well, having to put some sort to of time frame on how long you're gonna be on this planet. And figuring out, what is it I really want to do and can I accomplish that (Mark).

At the same time, because they came up with a new focus, much of what they did with their time was based on this philosophy. It was this combination of forces that frame the following changes in individuals relationships, families, work, lifestyle and health practices.

Because these individuals had a sense of urgency and a new value for deep relationships, relationships which did not have the intimate quality were terminated. The following dialogue between Mark and myself reflects this:

> (Mark) I'd say I'm a lot more demanding in my relationships with other people. I'm very impatient with superficial relationships. Actually I'm insulted by it whereas before I would go along with it and not say anything or do anything. Now when I'm interacting with someone, unless we get onto some sort of serious topic, I'm quite quick to terminate or move on to something else. ... It's kind of a sense that I don't have a lot of time, and that to get what I want out of my life, I have to do it now. I can't wait until I'm sixty to collect the rewards from my relationships.
>
> (Leanne) Do you find that you're successful in engaging in these relationships or how does it go?
>
> (Mark) Sometimes. I certainly am with other HIV positive people who have the same sense of urgency. But some HIV negative people, no. They may not be completely comfortable with it. They want to take their time or don't have a need to do or get involved in those kind of ways. I think it kind of weeds out the type of people I want to be involved with and the kind of people I really don't, quite quickly.

Similarly, before diagnosis, Jeff had a sense that some of his relationships were not what he wanted and said "the diagnosis just sort of put another nail in it. After diagnosis and during phase 1, I did a lot of weeding out friends".

There were also relationships that were lost simply because others could not accept or adapt to the fact that the individual was living with HIV. "But at the beginning it was really tough and, like I say, at first I lost people in my life and like that's okay. I think a lot of people do a lot of things out of pure ignorance and you just have to forgive them and let them on their way" (Derek).

> I have a really good girlfriend in London and we saw each other about a month ago for lunch here. And we were really close except for the natural drift when someone moves away. And she was very polite and friendly and that, but I don't think it sits real well with her. I think she was doing like a comparison - Jeff that I used to hang out with all the time and I really sense that split. That she is keeping touch but the bare minimum and I think she knows that the future is like in her hands and she just doesn't want to be too close to it. And that's fine. I can appreciate that. There are people like that. And she's still supportive in her own way as long as I get the odd call. Some people I never hear from (Jeff).

Even as relationships were lost, it was striking to hear the positive attitude in the individuals as they accepted and let things go. Relationships with friends were not the only ones lost. Family members also seemed to have troubles adapting to the information that their relative was HIV positive. "My one sister, I was talking to her when I was first out and diagnosed and I haven't heard from her since and I think that says it all" (Derek).

> My brother and my sister-in-law have kind of distanced themselves and I think I knew that might happen. I expressed some anger at them about them not understanding the issue or educating themselves. So

> they've kind of withdrawn, particularly around issues that are HIV related (Mark).

> I don't know if they [in-laws] really deal with the illness. I mean, my sister-in-law never called once and said how are you or do you need anything, so I don't know. They just go along like nothing's going on Or still, if I'm not feeling well, they'll say 'oh have you got that flu that's going around, or a cold?' And it's like, 'no, I don't. It's HIV' (Derek).

The losses and difficulties in the relationships, then, reflect either the individual's need for deep relationships or the inability of others to accept the diagnosis. Although some relationships were lost, the urgency and desire for intimacy also led to strengthening and deepening of some relationships. Jeff says that some of his relationships were "a lot more meaningful, more levelling, more honest." In Craig's story, his new focus, particularly valuing himself, led to positive changes in his relationships.

> Relationship-wise, when I'm dealing with friends and that, I'm a lot more open with them. I find it a lot easier to talk about, well, not necessarily intimate areas of others' lives, but more personal areas. Whereas it used to be very superficial; 'the weather's nice' kind of thing, but not much feeling and that's really changed.

The interactive nature of these secondary components is apparent in Mark's story as he said the relationships he has, their connections and depth, were very important to his self-esteem. Again this reflects the value he puts in relationships. Similarly for Craig, being able to engage in these close

relationships, reinforced his feelings about himself as more emotional, expressive and open.

Another area that certainly changed in some of these stories was their careers. In the stories of Mark and Jeff, with new priorities and a new sense of time, work played a very different role in their lives.

> I don't think I'm interested in my job the way I used to be. ... I think I'm putting a lot less effort into it because I don't think I'll be around for the pay off. I'm much less concerned about what my employer thinks, or working on projects or starting projects that take a few years. Whereas before, I may volunteer or seek out such projects that might look good on my resume. Whereas now I don't really care about that kind of stuff and would prefer something that I can enjoy now. ... And once I get to work I'm much more content to let work land on my desk rather than get up from my desk and go and make sure that everything is done and everything is caught up. That sort of thing. And much more likely to sit and chat with someone at lunch than I was before, where I was like, if this isn't a work related conversation, run along, because I have work to do. ... And I'm much more likely to take longer breaks and spend time with people when I do that. Rather than run out and have cigarette or run and get a coffee and come back to the desk and keep working. I'm much more likely to go find someone to have a break with or drag someone downtown for lunch (Mark).

For Jeff, the changed priorities and sense of time was like the catalyst he needed to change jobs altogether: "So when I left the industry - you know, I just couldn't be myself in that business, I just had too much else on my

mind - so I thought I've always wanted to bar tend so I did. A big change from banker to bartender." And then he made another job change, taking a job at an AIDS committee, where he felt he really had something to offer:

> So I needed to work but couldn't do what I used to do. I wasn't interested in doing it anymore you know. The reality of the diagnosis was I thought I'm not contributing anything to my growth or anyone else's growth. ... And had always thought I'd like a job in the AIDS field anyway, so I did.

Similarly, Derek's story related the values of work, contributing to the field of AIDS and the need to use one's time productively. Again the interaction between many of the components is seen in this example.

> Again what I do helps. The self satisfaction from that. And even there, you don't feel well and some days I think I should quit my job or go half time. But I know if I was sitting at home and didn't have this to look forward to, this sense of worth and contributing, that I would probably just get a lot worse. I would probably just curl up and die. So it keeps me going. So I'll stay here as long as I can. Unless there's some physical limitations (Derek).

Another change was the real emphasis on activities aimed at keeping oneself healthy. Again, here is the theme of time; developing a healthy lifestyle to extend one's time, and so that time remaining is quality time. Also, the motivation behind the health activities reflected the value of caring for oneself holistically -physically, emotionally, spiritually. Previous health activities, on the other hand, were motivated by external values of appearance.

I would say that before my diagnosis, my health interests were more related to attaining beauty. Exercising and stuff was because you wanted to be better looking. I think most of the things I do now for my health are directly related to HIV. I take vitamins because I'm HIV+, Chinese herbs, exercising are all because I'm HIV and slowing down the process. Whereas before it was for attractiveness. ... I drink a lot less. I go to the bar a lot less. I do a lot more yoga and try other things like riekki, therapeutic touch, massage. I'm much more moderate now - what I do, what I want to accomplish. I don't need to see the results. Not so concerned with the visual stuff of how I look (Mark).

So in essence, I do holistically, and a lot of things that I have never done before. You know, I'm on this whole vitamin mineral regimen and homeopathic thing that I do. And mind-body work, and stuff like that. ... I now do things like meditative breathing, and medications and visualizations, just sort of seeking some sort of your place in the universe (Derek).

I exercise consistently now. I used to be - I'd join the gym and I'd go for a while and then I wouldn't go for a while. But now I make sure that I take every opportunity I have to exercise and get out and even just go for a walk. ... Before it was like, should I be working out on weights or should I be taking aerobics. I didn't really know where I wanted to go, what I wanted to do. Whereas now I'm not really concerned about the body building aspect at all. I'm more concerned

about just my general fitness because I know that's what's gonna contribute to my health (Craig).

Finally, the lifestyle changes that Mark and Craig described, also reflected the new sense of valuing time and the focus that developed as a result of diagnosis.

> And, then, like now I spend more time on the phone, talking to my friends or going to visit my friends. I never go to the bar during the week anymore. And when I go on the weekend, it's when I know there's a gang of people that are going. I'm much less likely to go to the bar by myself now than I was before. And I spend a lot more time reading. I rarely watch TV anymore. I have two cats and like to spend time with them at home. I like keeping up with AIDS research I think that's pretty demanding. And being involved in the community. I often have meetings for that at night. Yeah, so my whole routine has really changed (Mark).

> And at times maintaining that, I mean I see other people with HIV leading somewhat self-destructive life styles. They don't - I mean they're still doing the drinking, the smoking and drugs, partying and stuff. And it's like do you really get enough out of that to make it worth it? But some people, that's all they live for anyway. So I guess quality of life is totally different for me than it is for them, I believe, biased probably (laughter). But I in part don't do those things because I want a good quality of life and a long life (Craig).

What emerged, then, was that participants developed a focus for living which emphasized caring about themselves, having deep relationships and contributing to the community. They also had a positive attitude and dealt with things in a new way. This, combined with new conceptions of time, led to several changes in one's story related to self, relationships, family, work, lifestyle, sexuality and health activities.

Illness

The third foundation element which changed the basic nature of their stories was the presence of illness as a result of HIV diagnosis When there was illness, when there was body breakdown and physical limitations, the rest of the story was greatly affected Illness is considered a fundamental component because of the huge influence it had on the rest of the story. While changing conceptions of time and life focus created many biographic changes, so too did the presence of illness.

The influence of illness was evident in the stories of Jeff and Derek. As said earlier, Derek was very symptomatic and Jeff had AIDS. In the following accounts, it will become clear that their conditions affected how they used their time, directed what activities they could take part in, influenced self-esteem and impacted on their relationships. Once again, changes in these components also affected one another, but the illness was still the director, behind it all.

First we see how time- another fundamental, structuring element of the story - was impacted by the presence of illness What an individual could do with time was often dictated by how he felt.

> I can get up in the morning and I will spend my first hour in the bathroom because since I've been up I've had like twenty bouts of diarrhea. And that can be physically draining. And that can make it extremely difficult. It's like I want to go back to bed all the time. It's that fatigue is always present. There's hardly a day goes by when at some point I'm not completely fatigued out. I think I'm obsessed with getting enough sleep. It feels like I can never get enough. That's brutal and if I have a free weekend sometime, I'll just spend the whole weekend in bed. Holidays that's all I do - sleep. So that's something new (Derek).

> But then there's other things too like just normal things. Like prediagnosis, let's load up the car and head off to the beach for the day and now it's like I don't think I can make it. So I missed out on most of the beautiful summer because I was too ill to drag myself off the couch (Jeff).

Illness and Secondary Biographic Changes

The impact of illness on secondary activities was equally phenomenal. The following statement by Jeff shows how much his lifestyle - daily routine of living - was affected.

> Now I always qualify everything I offer to do. I'll do what I can within my limits. So that's a loss. You know, even cleaning the house: if I vacuum this little room I'd be exhausted, I'd be in a sweat, I'd be achy; I'd probably have to sleep the rest of the day. So in terms of sharing an apartment we've had to make lots of adjustments. So certainly in the last month we've relied on volunteers and under some

pressure from ACCKWA. So we really discussed it and did we want to have people in our home doing things for you? So we just narrowed it down that the area we really needed help was meal preparations because I invariably have a lousy appetite. Or by the time I go and shop, I'm tired, and then to shop and come home and cook it, by the time it's ready I'm not hungry. It smells horrible and I don't eat.

Derek also talked about the changes in his lifestyle:
You might not know like five minutes before you go out the door what's going to happen or how you're going to feel. Or you could go to a party or gathering and you won't eat anything because it might hurt your stomach. I've got this thing with my brain and it just causes immense pain and you know I'm on pain killers and combination drugs and things and those things have an impact too. You know I tend to - my body temperature has gone like way up there so I sometimes profusely sweat where like I'm soaked. So that limits you from physically doing something. Like I can try to vacuum at home or something and I'll just be like wiped by it. ... Like I said, you can't really plan anything, you can't really say this is what I'm gonna do, even if it's a holiday cause then you're afraid you're gonna get away from home and feel really lousy. And like my brief case that I carry with me is like full of drugs and I can't leave that anywhere. I have to have it with me. Theres something there for everything. It actually becomes like a joke.

Illness also impacted on their social life and the relationships that were a part of their story.

> We try to go out once in a while but it is becoming much more apparent that Jeff and Bill always leave early. .. People call and say let's go out for supper or a beer and you know I can't do all that stuff anymore. So there's that whole lifestyle thing that's happening and in terms of relationships with friends and educating them and all that We've had a lot of discussion I guess on sensitivity and educating them. Some can buy in, some can't (Jeff).

Derek also experienced frustration with others as they were not able to adapt to his illness. "And then people don't understand, they say to you I look healthy and they can't understand that I have physical limitations I mean my old partner didn't understand that. Like I can't do what you do. I think people have a hard time with that".

> And when I'm not feeling well it's hard to communicate to people you know that it's not you, I'm not in a bad mood, because you're dragging yourself around, your energy is down and all this. So you're not as outgoing as you usually are, people always take that as a sign. So you're always reassuring people. And I'll take that opportunity to tell people, 'look I'm not feeling very well'. Just last week or the week before, I went to a birthday party for a friend because she means a lot to me and I did not want to go, I was not feeling well. And I sat at the table and I looked miserable and people were trying to offer me things and it was like 'no thank you I just want to sit there'. And then some people got really pushy and I had to say 'look I'm ill, I'm not well'. And if they push it further, I would say 'look I have HIV' and you

> know then, usually with that reaction, they'll take off and leave you alone (Derek).

The illnesses related to HIV also affected the secondary component of work in these two individuals' stories. For Jeff, it meant he could no longer work. The illnesses became too much, so he went on a disability pension. For him, this meant going from an income of around $75, 000 prediagnosis to a disability pension of around $10,000 a year. This difference, of course, affected his lifestyle, once again, demonstrating the interactive nature of these components. This interaction was also heard in Jeff's statement about how his self-esteem was affected by being on disability.

> So then having to give up work again and stay at home it was like, 'I know with the vanity up here that I can do this or I want to do this', but when it actually comes to doing it, your body doesn't want to do it. ... It's still hard sometimes when everyone else goes to work and you don't. Or you volunteer to do something but can never get around to doing it cause you feel so lousy.

Derek too, although he loved his job, at times felt it was too much and wondered about quitting or going part time. As well, because he worked at an AIDS committee where his diagnosis was well known, he felt pressure to prove he was well enough to continue to work. "And then in my work you're trying harder because people are aware of your condition and you have to prove yourself. So you have to make up for your sick days".

Finally, there was the impact of illness on sense of self. What was evident in the cases of Jeff and Derek, is that with illness, their self-esteem was definitely threatened.

> Your self-esteem, your physical image of your self really goes down I look at myself, my physical being or the way that I look and I think I look awful or that my body's this way, or that I'm bloated. You know, all of these things going wrong. And even other people, they see you and say you look good and I'm thinking, are they pulling my leg or what! Because on the inside I felt really lousy and I thought that must show through (Derek).

> I think that the losses sort of philosophy ties directly into your sense of worth because you have to put that into perspective. You know if your reality is the disease, you can't do what you used to do; you can't party as much, you can't cook as much, clean. All these things you just take for granted and all of a sudden, you have to make adjustments for that. It's like 'gee I'm not a very valuable person'. So there's sure blue days where you go through these feelings and it's just like putting it into perspective, and saying the reality is you can't, so get with it. So what are you gonna do to compensate for that (Jeff).

This final statement by Jeff also echoed the positive attitude that was discussed earlier. Even as these individuals dealt with illness and losses in many areas of their lives, they maintained an attitude of dealing with it and continuing on. They focussed on what they could do and not what they could not do.

Interestingly, Mark experienced a similar attack on his sense of self just as a result of diagnosis, as he was asymptomatic. Simply knowing the virus was in the body seemed like a threat to his sense of self and his sense of sexuality.

> Immediately after my diagnosis I was feeling pretty vulnerable, insecure about myself. Insecure about what I could do with my life and that kind of thing. ... I think I was quite afraid that my body would betray me, that I would start to lose weight or become ugly or start getting sick, that my appearance would fall apart sort of thing... Since my diagnosis, I think one of the hardest things for me to deal with is this feeling that I have been stripped of my sexuality; thinking no none would find me attractive anymore; not thinking of myself as sexual or thinking I am attractive.

Although Mark went on to describe how he has resolved these issues (which, as was discussed earlier, involved coming up with a new focus), it is interesting and important to see how just the initial HIV diagnosis triggered a similar processs to the presence of illness of attacking his sense of self.

What is presented here, then, is the view of illness, related to HIV, as a major determinant of one's story. Because of its great impact on so many areas -time, relationships, work, self esteem, lifestyle - it is considered a fundamental component of the biography. The presence of illness directed much of, though certainly not all of the unfolding story.

In summary, it was found that individuals talked about changes related to eleven areas of their life: time, focus, the presence of illness, relationships, families, work, community involvement, lifestyle, health activities and sexuality. The changes related to time, focus and illness were seen as directing the other changes. Changes in these three components had such an impact on the story, that the other eight changes could be understood as stemming from these primary changes. The changed sense of time altered the structure of one's story, particularly for the present and somewhat for the

future. The changed focus meant that new things were valued, as priority was given to self, intimate relationships and community involvement. Families became closer as it was felt that there was not the typical time line to allow family cycles and issues to be played out. Certain things were also 'let go': a fast-paced lifestyle that emphasized visual appearance and sexual relationships and relationships that lacked depth. Individuals developed a very positive attitude and began to explore new aspects of living. Individuals maintained a lifestyle and engaged in health activities aimed at keeping them healthy as long as possible. They went to bars less and began to use things like herbal medicine, riekki and were exploring their spiritual selves Finally, contending with illness put a strain on relationships and career activity and overall their lifestyle had to be adjusted. It was clear that the biographies of these four individuals were definitely impacted by their HIV diagnosis.

Chapter 5 - Theoretical Implications

The above analysis showed that an HIV diagnosis can lead to many changes in an individual's life. The four individuals' stories were certainly different after diagnosis. In this research, changes in the components of time, focus and illness were seen as directing many of the consequential biographical changes. I will now discuss how this framework relates to existing theory on biographic disruption and chronic illness. First, I will discuss how this research generally fits with other notions on biography, disruption and HIV. Next, I will relate the three foundation components that emerged in this research with existing literature. I will begin with a discussion of time. Next, I will relate the focus component to the concept of meaning which is discussed by other researchers. This will lead into a discussion of the relative importance of self in this research and as compared to other research. Finally, I will discuss the role of illness as it relates to HIV, focus, and theory on cognitive adaption and biographical work in general.

HIV and Biographic Disruption

To begin with, the concept of biographical disruption and impact was particularly useful for capturing the full, holistic impact of HIV on an individual. Bury (1982; 1988) suggests that the framework of disrupted biographies highlights how chronic illness affects body, self, the social world, our explanatory systems and our biography. The current research certainly supported this. Individuals noted changes in their physical health or awareness of health; they had become a changed person and talked about how their self-esteem had been affected; social relationships and activities had changed; they now had a new focus for living, a new way of approaching life and its events; and, they now perceived time and their unfolding biography in some new ways.

Furthermore, in their research with PHAs, Siegel and Krauss (1991) suggest that PHAs form a biographical script which "consists of projecting future life scripts that incorporate valued goals independent of illness while accommodating discontinuities caused by illness" (p. 28). Again, this was confirmed in this research. Individuals continued to have a sense of future and accompanying plans. HIV influenced this script, to some degree; the future was a more limited future and activities were affected by physical health or structured by the new focus the individual adopted. However, all individuals emphasized the importance of continuing to plan for a future, and thus, did not let HIV completely rule their life.

Time

The fact that individuals experienced changes in sense of time is not surprising. Time is a fundamental concept to biography, as one cannot talk about cumulative and projected life experiences without framing them in time (Corbin & Strauss, 1987). Furthermore, the particular reconceptions of time that were found in this research have also been noted by other researchers. In particular, Siegel and Krauss (1991) found that two major adaptive tasks for PHAs were "dealing with a sense of urgency to attain life goals" and "deciding to what extent to invest in the future" (p. 21). The urgency that they talk about is similar to the urgency discussed in this research: individuals felt a need to accomplish certain things before they died. The urgency is triggered by the fact that these men do not know how long they have to live but have a need to make the most of their remaining time. In terms of investing in the future, Siegel and Krauss (1991) found that their participants "typically reduced their career aspirations because of an unwillingness to expend energy and effort necessary to create opportunity to get ahead some time in the future" (pp. 21-22). A very similar attitude

toward work was expressed by Mark in this current research. In addition, although individuals did plan for a future, the plan was typically based on those values outlined in the focus component rather than on values and activities from their prediagnosis stage.

Furthermore, research on biography, chronic illness and other life shattering events suggests that following crisis onset, the past may take on particular importance for individuals (Corbin & Strauss, 1987; Koch, 1994; Taylor, 1983; Williams, 1984). The past is often reviewed in order to gain insight into the current situation and to give direction to one's future. It can involve rehearsing past successes or searching for the cause of the illness in past activities.

This phenomenon of reviewing the past was not found in the current research. Past time did not take on great importance for these individuals. The participants said they preferred to look the other way. This may have occurred for several reasons. First, Erickson's (1968) developmental framework suggests that in middle age generativity is a central task and concern for individuals. This means that persons are concerned with contributing to the well-being of future generations. Providing something or 'making a difference' for those who follow is important. It is possible that this is the stage that participants in this research were in. These middle aged individuals were very enthusiastic about participating in this research and saw it as an opportunity to contribute to the field of AIDS research and perhaps to improve the situation for other PHA's. Thus, as Erickson says is characteristic of this stage of development, the focus is on future generations rather than on reviewing one's own past.

Secondly, it is possible that the questions I asked did not adequately address the topic of past importance / review. Participants were asked if they

thought about the past differently. They typically responded 'no', that they prefer to look forward not backward. However, the fact that these individuals developed a new focus suggests that they must review past values and principles in order to determine their 'fit', or lack thereof, with the current situation and feelings. Thus, it may be that the full nature of past review / importance did not emerge because of questioning and interpretation problems. Perhaps individuals interpreted the question to mean did they think about the past in relation to how they may have became infected. This relates to the third point about this issue. Possibly, in the case of HIV, individuals do not focus on the past because it is much easier to locate causality and responsibility for the infection than it is with other illnesses. Other researchers looking at chronic illness suggest that people review the past in order to come up with causal explanations for their illness (Bury, 1982; Taylor, 1983; Williams, 1984). Their causal explanations are only speculative as they cannot be exactly sure why or how they became ill. With HIV, however, the mechanisms of infection are presumed to be well known and individuals may be able to determine with great accuracy why and when they became infected. Hence, reviewing the past may instill feelings of guilt, shame or regret. Such feelings are unpleasant and do not fit with the positive attitude which these individuals try to maintain. Thus, reviewing the past would not be nearly so important nor beneficial to these individuals. In summary, this research was congruent with past research which suggests that the present is more urgent and that a future is planned for but based on new values. It did not, however, support past findings that individuals will review the past.

Focus and Meaning

In reviewing the existing literature on chronic illness, the concept of meaning continually arises. Its exact definition and relation to chronic illness varies however. As will be demonstrated, some of the ways it is conceptualized are quite similar to the biographic component focus in this current research. The focus component was described as the individual's formulation of what is important to him and his attitude or approach to living. The term 'meaning' was not applied because it did not seem to reflect the concept the individuals were describing. Not once did they talk about searching for or finding 'meaning'; although at several points they said their focus, their philosophy, their attitude had changed since diagnosis. Upon further reflection, however, I agree that the focus component shares many similarities with the concept of meaning.

To begin with, the focussing concept seems quite similar to Taylor's (1983) conceptualization of searching for meaning. Taylor says that the search for meaning involves understanding the diagnosis in terms of implications for one's life. This search often leads to a reordering of priorities, a reappraisal of one's life. Taylor describes this as a "rethinking of one's attitudes and priorities to restructure one's life along more satisfying lines, changes that are prompted by and attributed to the cancer" (p. 1163). It often involves investing in new things now given greater importance and withdrawing from activities that seem to lose importance. As is heard in the following statement by Derek, this is precisely what the four individuals did in coming up with a new focus:

> And then there's learning to just let things go. You know, the little things in life that used to irritate me. They don't matter to me. There's just more important things to me. Just let it go and try to enjoy each

> day for what it is, for what you have, for the people around you. You try to find some small beauty around you.

In this light, if the search for meaning is understood as the search for and establishment of what is important, priorities and attitude, then the concept of meaning certainly applies to the present research.

The other aspect of a search for meaning that Bury (1982), Taylor (1983), and Williams (1984) discuss is the search for causality. They suggest that the onset of illness shatters previously held explanatory systems. As a result, individuals begin a search for meaning, asking why me, why now Williams suggests that following the onset of chronic illness, individuals will locate a cause for their illness that will typically serve to realign body, self and society. The search, and thus meaning, involves "linking up and interpreting different aspects of biography in order to realign present and past self with society" (p. 197). This aspect of meaning was less evident in this research. However Craig's story did reflect some sort of search for cause in past beliefs and attitudes:

> I realized that maybe that was a part of what led to my becoming infected in the first place was that looking for intimacy but finding it in the form of sex, which is the classical North American problem that we have from what I have read. That people go looking for that intimate contact and think sex is what provides that but in the end it doesn't.

For Craig, then, there was a questioning of previously held and popular beliefs about relationships. The result of this re-examination was new ideas

about relationships and what he wanted from others. Again this was part of his new focus - a new way of looking at and interacting in relationships.

Derek, Mark and Jeff also became politically active and very committed to community involvement which may reflect Williams' (1984) point that individuals will try to realign body, self and society. Although these individuals never explicitly linked the cause of their illness to societal issues (in the way that participants did in Williams' research), their diagnosis was like a spark or catalyst for them to get involved and advocate for their rights and challenge popularly held beliefs about HIV, AIDS, gays and lesbians.

This new commitment to political beliefs and community involvement can also be viewed as finding a purpose in the diagnosis. This is how Lewis (1989) and O'Connor, Wicker, and Germino (1990) define the search for meaning. They theorize that a search for meaning may involve a more philosophical purpose; it is an attempt to find a positive outcome for a negative event. In this research, Derek talked quite specifically about the purpose in his diagnosis. He felt that there was some sort of reason linking his previous involvement in the AIDS field and then his diagnosis.

> I just think that there's a reason. There's a reason I was put in this position and a reason I fell into all this. ... I never worked in social services or anything like that. And I remember those first few years I would think how did this happen, what am I doing this for? So I think it's becoming clearer. And then finding out my diagnosis. It was like 'wow, there's some sort of path here and some reason that I've been here'.

Finally, the current findings also relate to Fife's (1994) conceptualization of meaning. Fife suggests that the coping response to illness is constructing its meaning in relation to self and in relation to the social world. This too is what Bury (1991, 1987) calls the consequential meaning of a diagnosis. In the current research, the secondary biographical components, excluding changes in self, are like the contextual meanings of HIV. Participants had to come to an understanding of what HIV meant in terms of changes in relationships, lifestyle, sexuality, work, community, family, and health activities. Furthermore, they also had to come to an understanding of what it meant for self This reflects the process Fife calls "construction of self meanings" (p. 311). Participants talked about the impact of HIV on their self esteem and overall self concept, saying things like, "I'm more self confident; I'm kinder, gentler; I'm a more assertive person". In addition, just as Fife states, the interactional nature of self meanings and contextual meanings was also found in the current research. Feelings and thoughts about self were influenced by and influenced activities related to the social world. Thus, it is accurate to say that part of the coping response for the four PHAs was constructing the self and contextual meaning of their diagnosis.

Focus and Self

Literature on chronic illness has given great attention to self changes (Charmaz, 1983; 1987), and in this research, self changes and the ability to cope are linked to the focus component in some very important ways. As has been stated, the individuals' values, priorities and attitude (focus) influenced many of the biographic changes. Changes in self-esteem are tied to this because how one feels about oneself depends largely on what one values. Of course other external factors play on one's self esteem as well.

However, the influence of these external factors still depends on whether the individual places value on the contextual activity (a point which will be elaborated on shortly). For example, having fewer sexual partners does not have such a negative effect on an individual if number of sexual partners is not valued or linked to being a worthy person. So the effects on self esteem is determined by values and priorities (the focus) the individual has developed. This is not to suggest that the social world does not play a role in the development of expectations and values, as it certainly does. However, what was found in this research was that when diagnosed with HIV, previous values, based in the interaction between self and one's social world up until then, are challenged and often dismissed. Participants talked about 'looking in' in order to find out what was important to them Furthermore, after diagnosis these individuals became connected with an AIDS committee and a PHA support group. Thus, a big part of the social context that was influencing them was others who were living with HIV and had gone through the adaption process. Sandstrom (1990) notes that in these support groups, which are made up of somewhat ostracized individuals, the members will work to define themselves as different from society. This supports the current research finding that individuals released previous assumptions and values they had learned, in favor of new, more personally satisfying ones, based on the knowledge and experience of being HIV positive.

Furthermore, this connection between the focus and self is similar to existing literature on chronic illness and self change. Charmaz (1983; 1987) has demonstrated that with the onset of illness, the self as once known may become lost as the individual is no longer able to fulfil roles that were important to the self definition. Research specifically on PHAs has also found that following an HIV diagnosis there is often a shattering of identity

as the individual experiences losses related to work, relationships and strong emotional feelings related to their diagnosis (Sandstrom, 1990). When this shattering occurs, there is, however, an opportunity to construct new identities; the self gets redefined. Charmaz (1987) says that the individual with a chronic illness will construct "preferred identities". Preferred identities are like identity goals, representing people's feelings about who they would like to be, their hopes, assumptions and objectives. These goals, then, influence future behaviour: "in this sense, preferred identities serve as a source of *motivation*" (Charmaz, 1987, p. 284, italics in original) This, in essence, is like the focus component of the present research. In developing a focus for living, the individuals defined what was important to them, and, thereby, defined what type of person they wanted to be. Future behaviour, and thus many biographic changes, reflected this focus development

Illness and Focus

The above discussion described how the focus component was influential on the individual's identity The presence of illness also played a defining role on identity. As was seen in this research, no longer being able to work, care for an apartment or continue to socialize with others can certainly challenge one's sense of self. This represents the point that past research on chronic illness has made: when illness sets in, forcing roles to be lost, one must come to a new understanding of self and of one's remaining life (Bury, 1982; Charmaz, 1987; Corbin & Strauss, 1987). The present research highlights two important, inter-related points in connection to this. First, the impact of losses and changes related to illness is influenced by focus changes. For instance, if an individual has decided that career is no longer important to him (focus level change) then the impact of not being able to work due to illness will be lessened. This point bears great

resemblance to Taylor's (1983) cognitive adaption theory. She suggests that successful adapting to threatening events involves finding meaning in the event, gaining mastery over the event or some aspect of life, and by working to enhance one's sense of self. She suggests these tasks are accomplished by "looking at known facts in a very particular way" (Taylor, 1983, p. 1170). In order to adapt, the individual must cognitively restructure how he /she will view and interpret things. I believe that a similar process occurred with individuals in this study. By creating a new focus, individuals evaluated experiences based on new criteria. Therefore, if activities or aspects of self were lost (because of the presence of illness), but were evaluated within a new framework that puts less value on them, the loss was no longer so devastating. The cognitive restructuring in this is that the individual is definitely selecting what 'way' to look at the information. And, just as Taylor insists, I am in no way suggesting this is faulty or problematic. In fact, my experience with these four individuals suggests just the opposite. Having this new focus - a new framework for evaluating experiences - seems extremely adaptive and important to the mental health of these individuals.

Illness and Biographic Changes

Secondly, this research demonstrates that it is not necessarily illness or body breakdown that produces many of the self and contextual changes. Past research has typically focussed on how physical changes impair one's ability to fulfil roles and, thus, continue one's identity presentation. As a result, biography, in terms of who I am and what I can do now and in the future, changes and is different to that of the past. This, in essence, is Corbin and Strauss's (1987) model of biographical disruption:

> The impact of body failure and consequent performance failure can be measured by the impact that it has on each dimension of the BBC.

> Since each dimension (biographic time, body conceptions, conceptions of self) exists in a tightly bound relationship with the other, the consequences of body failure with regard to one aspect are further felt with the other two. It is the combined impact of the three aspects of the BBC that profoundly affects biographical continuity and meaning. (p. 260)

The framework used in this current research is not a direct reflection of this model because of the opportunity to observe biographical changes as a result of diagnosis, in the absence of body breakdown. This is because of the fact that, with HIV, people often get tested and diagnosed before there are physical symptoms alerting one to the possibility of illness. This is different to most other chronic illnesses where diagnosis usually follows some physical indicator that there is a problem with the body.

The present research, found that even in the absence of body changes, continuity and meaning of biography was still altered This was heard in the stories of Mark and Craig. While these individuals had experienced no illnesses related to HIV, they had experienced many changes related to time, focus, self, relationships, work, sexuality, lifestyle, and community and health activities. Thus, in this research, the diagnosis alone triggered the process of rethinking time, what I want out of life, who I am, what I value and what sort of person I want to be. Furthermore, Mark's story is a very striking example of how diagnosis - and the absence of body failure - can cause changes similar to those created when there is body breakdown Mark said that simply when diagnosed he felt "vulnerable" and "wounded" "I think I was quite afraid that my body would betray me, that I would start to lose weight or become ugly or start getting sick, that my appearance would fall apart sort of thing."

Jeff too said that when he was first diagnosed it "was like a real dive: felt that I was a low life, dirty". This demonstrates that diagnosis alone can cause changes in one's sense of self and self-esteem in particular.
This is not to deny that when illness is present, as was heard in the stories of Jeff and Derek, the continuity and meaning of biography is definitely altered. There is no question that for these individuals, their stories, their lives, were greatly affected by having to manage the physical aspects of HIV. However, this research demonstrates that even in the absence of illness, the diagnosis alone can trigger changes to the biography.

What is presented, then, is that in the case of HIV, biographic disruption may occur in ways different to other chronic illness. While with other illnesses body breakdown usually coincides with diagnosis, with HIV there are not necessarily physical problems at the time of diagnosis. However, even in the absence if illness, many components of biography are still impacted. This is primarily due to the fact that conceptions of time and one's focus for living change as a result of diagnosis which in turn affects the unfolding biography. It is also due, in part, to the fact that, at least initially, a diagnosis can carry the same impact as bodily limitations.

The above discussion shows how this research relates to existing theory on chronic illness and biographical disruption. While many similarities were found, the impact of diagnosis alone for one's biography is particularly significant and different to past conceptualizations. In addition, this research's relevance to Taylor's (1983) theory of cognitive adaption may be particularly useful for understanding how PHAs adapt to their diagnosis. Thus, this framework will be elaborated on and related to clinical practice in the following chapter.

Chapter 6 - Social Work Implications

The individuals interviewed for this research seemed to find a way to incorporate their diagnosis into their biography in a very healthy and enriching way. In all four cases, when the interview was ending, I commented to the participants on how well I thought they had adapted to their diagnosis: how they had seemed to make so many positive changes. The participants agreed, saying that they felt their life was better, more fulfilling now compared to prediagnosis. They also said that they felt quite atypical in their experience of HIV and ability to adapt: that many others were not able to do this. Indeed much of the literature on PHAs would support this, as thoughts of suicide and suicide rates are much higher among PHAs compared to the general population (Health and Welfare Canada, 1992). As clinical social workers, I believe there is much to be learned from these positive experiences. In particular, for clinical practice, I believe this work and these men's experiences relate to the theory and practice of narrative therapy (White & Epston, 1990). The self emergent narrative process they went through is consistent with the principles and processes used in narrative therapy. Thus, I will show why narrative therapy may help other PHAs adapt to their diagnosis. In addition, I will show how these men's experiences highlight the importance and need for social workers to use a community development approach when working with PHAs

Clinical Implications

Earlier I argued that by creating a new focus for living, participants were able to avoid many of the possibly detrimental psychological effects of their diagnosis. If they did not value those things that were lost due to diagnosis (i.e. a fast-paced, success oriented lifestyle), the impact of the losses was not quite so negative. Similarly by valuing those things they

could accomplish, a positive sense of self was maintained. This process was viewed in terms of Taylor's (1983) theory of cognitive adaption; by looking at information a certain way and interpreting it within a certain framework, individuals were able to adapt.

While Taylor (1983) suggests that this adaption occurs through specific cognitive efforts and restructuring, within narrative therapy, it can be viewed as based on the construction of an "alternative story" (White & Epston, 1990). Like this research, narrative therapy asserts that individuals couch their experiences in their own story and thereby ascribe meaning to their experiences. Therapy from this perspective aims to assist individuals to talk about those experiences not commonly included in their story, as certain aspects are always left out. In doing this, the therapist is looking for "unique outcomes" - times when the individual was not influenced by the problem. Based on these unique outcomes, the therapist works with the client to construct an alternative story (O'Hanlon, 1994; White, 1989; White & Epston, 1990).

Michael White's work and theory of narrative therapy was largely influenced by the thought of Michael Foucault (Madigan, 1992; White & Epston, 1990; Wylie, 1994). It is in this connection that the current research relates. Foucault has argued that through dividing practices (social and spatial separations of certain individuals), scientific classification (labelling) and subjectification (an individual's own identity formation that is constructed through internal dialogues which are based in cultural norms), that individuals influence and are influenced by the dominant culture (Madigan, 1992). These practices are based on, and support, 'global' or 'unitary' knowledge, which is cultural knowledge. This knowledge is given support or emphasis, and thereby survives and is seen almost as 'the truth'.

At the same time, however, there exists alternative knowledge or 'local' knowledge which is not given the same mass support and is often silenced (Madigan; 1992; White & Epston, 1990).

Narrative therapy aims to uncover the local knowledge and thereby help "free" the individual from the destructive aspect of the dominant knowledge. It is from the local knowledge that the alternative story is then created.

I suggest that in this research, the process whereby individuals developed a new focus for living, involved precisely this movement away from global knowledge and toward local knowledge. They released previously held values such as a fast-paced, success oriented lifestyle with emphasis on external beauty, money and sex, and came to value relationships, contributing to the community and themselves. Behaviour, and thus their stories were driven by these new values. Furthermore, as has been stated, this shift in perspective - this movement from the dominant story to an alternative story - was very adaptive and health promoting for these individuals.

Thus, based on the experiences of these four individuals it seems that being able to create an alternative story helps PHAs to cope with their diagnosis. For these individuals, the alternative story was based in new values and a particular approach to living. Narrative therapy can be used to help other PHAs question the values that become internalized and drive the dominant story:

> Many of the beliefs and thoughts we cling to most dearly are nothing but a vast cultural ragbag: lines from old love songs, *Glamour* magazine layouts, advertising jingles, romance comics, 'Dear Abby' columns, stern lectures from our fathers about what it means to be a

> man, memories of old love affairs, childhood days swimming at the river. We have unconsciously absorbed beliefs that we aren't good enough, that worthwhile people know how to dress or cook fresh pasta; that only thin women are beautiful or worthy; that real men know how to keep a woman 'in line'. If we consciously learn to recognize the insidious effects of these beliefs, [narrative therapists] argue, and see them as not inherent to ourselves, we can free ourselves from them. This the kind of 'liberating conversation' that [narrative therapists] hope to have with their clients. (O'Hanlon, 1994, p. 24)

In recognizing the insidious effects of cultural knowledge, narrative therapy aims to uncover the political forces that led to and were supported in the dominant story. The goal is to help the individual understand how certain institutionalized ways of thinking and behaving were in fact counterproductive to their health (O'Hanlon, 1994). This is very congruent with the experiences of the four men in this research. As was stated earlier, for the four individuals interviewed in this research, part of creating a new focus was realigning self and society, examining previous belief systems, and becoming politically active and involved in the community. Thus, as was seen in this research, understanding and acting on one's new political awareness may indeed be important to re-establishing wellness after diagnosis.

In narrative therapy, helping clients see these values - or any problem - as external to them is essential to the process. "Externalization basically entails a linguistic separation of the problem from the personal identity of the patient" (O'Hanlon, 1994, p 21). The person is never the problem. With PHAs, externalization can be useful in examining examine values, as was

seen in this research, but also as a way to gain perspective on the diagnosis in general. With this approach, therapists would help PHA's see themselves as separate from their diagnosis. HIV would be seen as an aspect of their life, but it would not be their whole identity. This is congruent with the work of Corbin and Strauss (1987) who suggest that part of reconstructing one's biography following diagnosis is contextualizing the diagnosis; integrating the diagnosis as part of the self, but not allowing it to be the self. Using narrative therapy, the focus would be on how and when they continue to live well despite the influence and presence of HIV. Rather than focussing on the person in the sick role in the dominant story, this therapy would look for the other aspects of identity, the unique outcomes and instances. It would be these occurrences that create the basis for the construction of the alternative story. "People's present lives cannot be reduced to their diagnosis, which are much too tight, too confining to contain the capacious possibilities revealed in their histories" (Wylie, 1994, p. 43).

The principles of narrative therapy, then, can be very effective for working with PHAs who are having difficulty adjusting to their diagnosis. The men in this research demonstrated how constructing an alternative story based on a new focus for living can help adjustment to diagnosis and be health promoting. These individuals discarded much of the dominant cultural messages about what is important and valuable and came up with new priorities that were more congruent with their feelings and situation. Using the narrative techniques and philosophy of externalization, other PHA's can work through a similar re-examination and re-evaluation process in order to help them adjust to HIV. As well, using externalization and the construction of alternative stories, PHA's can be assisted to recognize and act on aspects of their identity that are not consumed in their diagnosis.

Community Development Implications

On top of its relevance for direct clinical practice, this work and these men's experiences also relate to community development practice. In particular, the community development approach to social work has advocated seeing beyond the individual's 'problem', and drawing on the skills, knowledge and experience of community members in order to address the larger social issues behind individual problems (Campfens, 1987; Lappin 1985, Rothman & Tropman, 1987; Young, 1987). Such an approach recognizes the inherent value in all members of society and emphasizes that member participation leads to a sense of empowerment in the participating individuals. In this way, individual well-being is maintained through very different practices than individual therapy.

> By linking themselves to one another, individuals can move from a naive state of consciousness to reflecting critically on their collective condition, sharing their individual insights and experiences and thereby check the correctness of their perceptions. Second, they can gain support from one another in mutual aid and self-help efforts and become mobilized to experience a sense of personal control. Eventually they may take group action toward achieving social change in a societal context. (Campfens, 1987, p. 133)

This is precisely what occurred with three of the men in this research (and the fourth expressed his desire to take part in community activities). The individuals connected with the local AIDS committee and thereby connected with other individuals dealing with the diagnosis and similar issues. On top of gaining support from these relationships, it also motivated these individuals to become involved at the community level. They were on

committees for AIDS at the local, provincial and national level; they did a lot of public speaking about their experience; they advocated and lobbied for their rights; they developed new skills and abilities and all of this seemed to greatly enhance their well being and overall level of adaptation. The individuals stressed how important this involvement was to them and it seemed critical to dealing with their diagnosis.

Thus, as social workers, it is important that we not only look at working with PHA's on an individual level. This work demonstrates how valuable it is to both the individual and the community to have those directly affected coming together and working around the issue. Particularly for those of us trained in clinical practice, it is important for us to make a conscious effort to include community development principles in our practice:

> From the perspective of the professional it takes a considerable leap to move away from our inherent and learned tendency to take control of a client situation, and function in an expert-like fashion as case or organizational managers, toward objectives that aim in nurturing community among people, at liberating the mutual aid potential, and allow for human creativity and innovation to surface (Campfens 1992, p. 8).

Based on this research then, two approaches to social work practice with PHAs are suggested. At the individual level, the principles and techniques of narrative therapy are appropriate for helping individuals question previously held beliefs, both generally and related to their ascribed role as 'a sick person'. In finding alternative values and ways to view themselves, PHAs can construct a more self-satisfying, healthy, and adaptive

story In doing this, and / or in uniting individuals with other PHAs, political awareness may be heightened, moving the individual to became involved at the community level. Through contributing at this societal level, the value, knowledge and experience of the individual is reinforced and thus is another way to help enhance the individual's adaption to his diagnosis. These two approaches in no way need to be mutually exclusive. They may be useful separately, be applied together, or one may follow the other. For instance, when an individual first contacts a social worker, the social worker may link him up with other PHAs, thereby mobilizing potential mutual aid and community involvement. In these interactions, individuals may begin to go through a questioning or re-evaluation period and want to work through these issues in individual work with a therapist. Similarly if individual work is begun first, in the process of questioning the dominant story, political awareness may be raised. From this, the individual may want to be connected to others with similar feelings and to an arena for political action aimed at change Thus, narrative therapy and community development approaches may be extremely useful to social workers working with PHAs.

Chapter 7 - Conclusion

This exploratory research looked at how an HIV diagnosis impacted on the life story of four gay men It was found that their diagnosis changed their stories in eleven areas: conceptions of time, their focus for living (defined as their values, attitude and approach to living), the presence of illness, relationships, family, work, lifestyle, community involvement, sexuality and health activities. It was further shown that changes related to time, focus and the presence of illness played a particularly significant role in the resulting biography, giving direct shape to the story and influencing the other eight changes. These three components were seen as primary changes and the other eight, secondary.

This conception of the biographical impact of HIV was congruent with much of the existing literature on the impact of chronic illness on an individual This research supported existing theory that suggests when diagnosed, individuals will form new conceptions of time and that they will search for meaning. For these individuals, the present had a sense of urgency, and the future, while definitely planned for, was seen as somewhat limited. The past was generally irrelevant for these individuals. Meaning was sought in terms of determining what was important to the individual and establishing an approach and attitude toward living (the focus component). Furthermore, as other research suggests, when illness was present it definitely impacted on these individual's lives However, in this research it was also found that, even in the absence of illness, the HIV diagnosis alone, impacted one's story.

It was also seen that developing a new focus for living was particularly adaptive for these individuals. Based on this, it was argued that narrative therapy may be a particularly useful model for therapists to use with PHAs

who are experiencing difficultly adjusting to their diagnosis. Just as the individuals in this research re-evaluated and came up with new values, narrative therapy can help other PHAs question values and views that are maladaptive when living with HIV. As well, it was argued that social workers must work to link PHAs together and encourage and support their community involvement as such activity was extremely important to the well-being of the individuals in this research.

The small number of people interviewed in this research was definitely a limitation of the research. Unfortunately it meant that the point of saturation could not be met in the data collection or analysis. One way this problem could have been minimized was by doing repeat interviews with the participants. This would have been beneficial as it would have allowed me to explore with participants topics that other participants discussed. For instance, only after gathering and beginning to analyze my data did I realize that the topics of sexuality and the search for the cause of infection were each only addressed with one individual. Thus, by going back and conducting second or third interviews, more overlap and thus saturation could have been established. As well, conducting more than one interview may have allowed a stronger relationship to develop between myself and participants. Hence, participants may have felt more comfortable sharing some of the painful feelings they have experienced as a result of their diagnosis. The individuals interviewed certainly portrayed a very positive image of their lives since diagnosis. This was congruent with the positive attitude they had adopted, and in fact, one participant specifically said that this positive image - as opposed to an image of victims - is the one he wanted to provide. Perhaps if further interviews were conducted, participants may have felt comfortable sharing other aspects of their experience of living with HIV. In fact, in

providing feedback on the research process, one participant said he wished a second interview was conducted. He said that the initial interview 'got him thinking', and he would have had more to share, had I interviewed him again.

Related to this, I think it would be important for this research to be conducted by someone more familiar with or a part of the gay culture. Being a straight female meant that I did not know the culture and, thus, may not have been told certain things that a gay man may have been told Possibly sexuality issues would have been discussed more if the interview was conducted by a member of the gay community. Furthermore, an important question not addressed by this research is what is the combined impact of being HIV positive and gay in a heterocentric society? It may be that some of the biographic changes found in this research were a result of being gay rather than HIV positive. In addition, this research did not address the "stigma" and negative societal treatment that PHAs still experience. Derek pointed out that this is still a common experience that PHAs must deal with Perhaps the fact that I am not HIV positive nor part of the gay community meant these issues were not discussed with me

One of the ways I tried to compensate for this difference was by conducting a member check (Lincoln & Guba, 1985). Part of the reason I gave my analysis back to participants was to make sure that I had not misinterpreted any of their experiences that may have had more to do with gay culture than I knew. Having the participants review the analysis was also important to counterbalance the fact that I did not have anyone else code the material. By giving the material back to participants, I was asking them to check my interpretation; were the codes and the theory I applied appropriate to them based on their experience. Thus, the analysis and interpretation were

not based solely on my thoughts, but had to 'fit' with the perceptions of the participants.

This research also led to some interesting questions that should be explored in future research In particular it was a curiosity that I had to initiate discussion related to family and thoughts on the past. While I offered some ideas as to why individuals did not seem to reflect on the past, further exploration related to this and the role of family for PHAs is needed. Furthermore, something that emerged from this research was that initial diagnosis presented great crisis for these individuals. The participants talked about being in shock, not sharing their diagnosis with others, thus dealing with it alone, and generally, great despair thinking that they were about to die Although these individuals went on to 'recover' and understand more fully what this diagnosis meant for their life story, the initial shock and fear is certainly a concern. This highlights the importance of and the need for positive and supportive methods for sharing the initial diagnosis, and providing the individual with accurate information about the implications of his diagnosis.

Based on my experiences, I would certainly suggest that further research on psychosocial aspects of HIV also involve qualitative methods Conscientious use of qualitative methodology allows research to give power to the participants. It underlines the importance of ensuring that the researcher and the participants are equals, of being responsible with research and ensuring that what is said and done with the research is congruent with participants' feelings and concerns. The emphasis is on using the research to empower rather than disempower the population being studied (Kirby & Mckenna, 1989). This is particularly important to, and necessary with research on HIV / AIDS PHAs often feel powerless in living with HIV.

Control can be of great concern to these individuals since they may be losing control over many aspects of their life. Thus, a methodology that gives emphasis to their experience, gives control over the process to them, may work to empower the participating PHA's.

My experience in doing this research particularly reinforced this point When I worked at an AIDS committee (not the one that I had contact with for this research), I was in a professional role and, whether I liked it or not, I was viewed as the person with power. PHAs came to see me when they were in crisis, in need of support and / or in need of resources. I felt that there was a lot of resistance on the part of the PHAs about coming to the committee for assistance. Asking for support may have reinforced their sense of continuing loss of control. This experience was also echoed by some of my colleagues and Sandstrom (1990) has touched on it briefly in his work.

This work experience is contrasted with my experience in doing this research. As a student, I definitely was not viewed as being in a powerful position. Participants, rightly so, were the experts, the ones with the knowledge. It was I who needed the help of these individuals for the completion of this project. Interestingly, with this reversal of roles, I found that the individuals were more than willing to talk in depth about their experience. Furthermore, each of them thanked me for the opportunity to tell their story and appreciated the emphasis on their experience and the flexibility in the interview process. I think this highlights the need for conscientious efforts aimed at breaking down power barriers in research and in practice.

Finally, I feel that this research emphasizes the amazing capacity of people to adapt, cope and find the strength to survive. I am often struck by

the paradox that HIV /AIDS presents: frequently, individuals become infected when engaging in an act (sexual activities) that can provide a sense of belonging and closeness with others. While attempting to have these basic human needs met, individuals get infected with a virus that often leads to isolation, stigmatization and usually an early death. For a long time, I, like many other individuals, thought that the diagnosis would directly lead to this harsh reality. The experiences of the four individuals interviewed in this research, however, demonstrates that a rich and fulfilling life can be maintained after diagnosis. In what might be thought of as a crisis, a life shattering situation, there is an incredible ability to adjust and find the value and strength in oneself, one's relationships, and in life.

Appendix A

Script for telephone conversations with interested participants

"Thank you for calling. I'll tell you a little about myself and the nature of this research and then you can ask any questions and we will decide if this is something you'd like to take part in. Does that sound ok?

(response)

My name is Leanne Baird and I'm in the final year of my Master's in Social Work which I'm doing at Wilfrid Laurier University. Part of my program requirements is to complete a thesis. I have chosen to do my thesis on how an HIV diagnosis affects an individual's life story I want to do this because I've done a lot of reading on HIV and am working at an AIDS committee and want to learn more about the experience from the perspective of someone dealing with it.

Participation involves an interview with me that should take between 1 and 2 hours. Also once all the interviews are completed and the information analyzed, I will have another meeting with you to check that you agree with what I have written. In the interview, I will be asking you questions about what your life is like now that you have been diagnosed with HIV, and just want to openly talk about changes in you, your relationships and your life in general. It will be fairly unstructured and I hope that you will feel comfortable talking about your experience. Before we begin the interview, I will go over with you how I plan to keep you identity anonymous and how confidentiality will be ensured, and what some of the risks and benefits of participating are and what your rights are in participating. There is also a form with this information that you will be asked to sign and can then keep.

It will have my telephone number so if you ever have any questions you can call me".

"Do you have any questions you want to ask me now?"

(Response - If individuals want more specifics on confidentiality or risks and benefits, I will give the information from the informed consent form)

"Is this something that you would like to take part in?"

(Response and if yes, date and time for interview will be arranged)

Appendix B

INFORMATION ABOUT THIS STUDY / CONSENT FORM

I understand that I am being asked to participate in a research study which is being conducted by Leanne Baird a masters of social work student, under the supervision of doctor / professor Juanne Clarke (a professor in medical sociology) and the Faculty of Social Work at Wilfrid Laurier University

The purpose of this study is to better understand the impact of an HIV diagnosis on an individual's life: how one's self, one's social relationships and one's whole life may change or been seen differently after diagnosis with HIV. The data collected in this research will be used to promote this understanding.

The following procedures will be used: I will engage in an interview with Leanne Baird where I will be asked to share my experiences and talk about the impact of my diagnosis. Once all interviews are complete, the information gathered and interpreted, I will again meet with Leanne to discuss the work and give feedback on the final product. This is to ensure that I am comfortable and agree with the interpretations and use of my experience. I understand that the proposed length of my participation in this study is approximately 2-3 hours.

I understand that the following risks are involved in participation. I am being asked to talk openly with an unfamiliar person about my experience with HIV and that questions pertaining to this may be asked of me. This

conversation may be difficult and trigger strong emotions. Furthermore, even though steps are being taken to ensure my anonymity and confidentiality, my "story" will be shared and read by others who I do not know I understand that I am free to contact the investigator at the telephone number listed below if I have questions.

The following are benefits which I may derive from my participation in this study:

- I am contributing to research in HIV, which may help professionals working in the field and improve the situation for others living with HIV
- I will have input into the final product of this research thereby ensuring the accuracy and legitimacy of what others are reading and learning
- I will learn about how HIV is affecting others
- I will gain knowledge on how research is conducted in the field of social work

I understand that my participation is voluntary. I may refuse to participate in this study without penalty to me. I may also withdraw from the study at any time without penalty or loss of benefits to which I would ordinarily be entitled. I may omit the answer to any question.

I understand my research records will be kept confidential and that I will not be identified in any publication or discussion.

I understand that direct quotations may be used in reporting the data. The use of these quotations will be limited to those that do not disclose my identity.

The researcher will obtain my consent to use quotes that may disclose my identity.

I understand that I have a right to all questions about the study answered by the researcher or research advisor in sufficient detail to clearly understand the answer.

I understand that I can receive feedback on the analysis and overall results of this research. I will be invited to a second meeting with Leanne in January (or as notified) to discuss the findings and may receive a final copy of the research in April.

If I have any questions about the research, the procedures employed, my rights, or any other research related concerns I may contact the investigator and/or their supervisor.

I acknowledge receiving a copy of this informed consent.

_____ _____

_____

Investigator Participant

Telephone #: _____

(Supervisor's name and Investigator's or Supervisor's phone number)

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Table 1

Components of change following HIV diagnosis

Topic	Discussed by	Topic initiated by Participant	Myself
1. Time	Mark*	X	X
	Jeff		X
	Derek		X
	Craig		X
2. Focus	Mark	X	
	Jeff	X	
	Derek	X	
	Craig	X	
3. Presence of Illness	Jeff	X	
	Derek	X	
4. Self	Mark	X	
	Jeff	X	
	Derek	X	
	Craig	X	
5. Relationships	Mark	X	
	Jeff	X	
	Derek	X	
	Craig	X	
6. Family	Mark		X
	Jeff	X	
	Derek		X
	Craig		X
7. Health activities	Mark	X	
	Derek	X	
	Craig	X	

Table 1 continued

Topic	Discussed by	Topic initiated by Participant	Myself
8. Community Involvement	Mark	X	
	Jeff	X	
	Derek	X	
	Craig	X	
9. Lifestyle	Mark	X	
	Jeff	X	
	Derek	X	
	Craig	X	
10. Work	Mark	X	
	Jeff	X	
	Derek	X	
	Craig		X
11. Sexuality	Mark	X	

*In this case, I have indicated that both Mark and I initiated this conversation because he began the conversation related to present and future time, while I initiated the discussion on past time.

Figure 1

Interaction of primary and secondary components